

LIFE AFTER HISSOM



► OKLAHOMANS WITH RETARDATION: FROM INSTITUTION TO COMMUNITY

SPECIAL REPRINT

Two Muskogee Phoenix writers drove several thousand miles and conducted more than 120 interviews during a three-month investigation into the state's efforts to close Hissom Memorial Center. The result was a five-part series titled "Life After Hissom" that the Phoenix published July 7 through July 11, 1991. This is a reprint of that series.

► PART ONE

Hissom case costs climb to nearly \$40 million. A Hissom class member has made dramatic progress since leaving the institution. Life at Hissom has improved for clients; problems remain.

► PART TWO

Incestuous ties between consulting companies and out-of-state experts. Millions of taxpayer dollars leave state. Philosophies clash over posturing of clients. Spending unchallenged. A father's frustration.

► PART THREE

Hundreds of Oklahomans with disabilities go unserved. Two mothers of children with needs face enormous obstacles daily. A controversial model plan.

► PART FOUR

Hissom clients are being placed in the community without adequate safeguards. One wound up in court. Client exercises his new rights — he frequents bars. Abuse continues to plague system.

► PART FIVE

Attempts to solve some of the problems are under way. New DHS director and attorney for plaintiffs in Hissom suit speak out. Client is experiencing life in the community with success — he's making a paycheck, learning to live on his own.

"The companies could have had them out, but why would they put them out if they could rake in the dollars and do it very slowly. A lot of legislators feel like these people were taking the money that actually goes to these mental retardation programs."

Herb Rozell
state senator

"Hissom became a feeding frenzy. The sharks got meaner and fatter. Some were nice, polite, understanding, but it didn't matter. Armed robber or panhandler, they still took our money . . . they still raped us."

— Phillip J. Allen, a pharmacist at Hissom Memorial Center, seemed to sum up the feelings and frustrations of Oklahoma mental health workers in a satirical essay. The writing, distributed to fellow Hissom employees, was Allen's view that "carpetbaggers" had come to Oklahoma and taken advantage of a court order com-

Court order's tab hits \$190 million

By KRISTI FRY and
DONNA HALES

Phoenix Staff Writers

Oklahoma has spent \$190 million — 10 times more than reported — in four years trying to satisfy a federal court order to close Hissom Memorial Center.

The state is struggling — often recklessly — to build a community support system for people with mental retardation. Unprecedented spending targets a select few while thousands of Oklahomans are left adrift to fend for themselves — financially and emotionally.

Despite a nationwide trend to community care that began decades ago, Oklahoma failed to act. Now, taxpayers are paying the price of procrastination.

After a three-month investigation by the Muskogee Phoenix, a five-part series, titled "Life After Hissom," begins today. Parents, advocates for people with mental retardation, and high-ranking state officials — all frustrated with the lack of state oversight and their inability to do anything about it — were anxious to have this story told.

The series will reveal:

- Until March 1991, the Oklahoma Department of Human Services was spending millions of dollars without knowing or questioning what it was paying for. It was a lucrative arrangement for private firms, mental retardation experts and others recruited to help meet court-ordered demands.

- Extravagant spending on a model plan the state could never afford to use as a pattern for its programs: more than \$2 million to serve seven clients for two years.

- State legislators, bombarded with allegations of abuse and wasteful spending, have ordered a Senate investigation. It may begin this month, said Sen. Herb Rozell, D-Tablequah.

- Nearly 600 people with developmental disabilities and mental retardation, eligible for help, are being denied services. Hissom is consuming all of the resources.

"I don't think that just because a child was at Hissom, they deserve more than my kids do," said Sandy Ronk of Tulsa, mother of two children with severe disabilities.

■ Abuse of Hissom clients placed in the community by caretakers, including the alleged rape of one client and alleged repeated beatings and neglect of another. There have been other abuse allegations. 44 through May 1991.



A MOTHER'S HUG is a new experience for Renee Parker, 10. Miriam Jett, her foster mother, pre- scribes love in massive doses. Jett rescued Renee from a life of institutional care.

- Preferential contracts were given to out-of-state firms and mental retardation experts with incestuous ties to each other. Some testified in the Hissom court case that programs were needed, then were hired to oversee them.

- By the end of May, DHS had moved 125 Hissom clients into the community. More than 270 remain at Hissom as an October 1994 deadline to place all clients approaches.

- DHS failed to meet a court deadline of June 1990 to establish safeguards and emergency services for clients in the community. A safety net still is not in place.

Rozell and Sen. Lewis Long, D-Glenpool, co-authored a bill to investigate a year ago, but it was (See RETARDED on Page 4)

Retarded move into community

(Continued from Page 1)

vetoed by then Gov. Henry Bellmon. Gov. David Walters vetoed the bill this year, but the measure was placed in a different bill and enacted, Rozell said.

"We want to look at excessive expense — but in no way interfere with the judge's ruling concerning placement of these people," Rozell said. "The Legislature is committed to the consent decree."

Rozell and Long want to know why no one was reviewing bills before they were paid.

"They could have done as much on a lot less tax dollars. There needs to be someone checking those invoices before payment is made."

Said new DHS Director Benjamin Demps Jr.: "I hope, that as we prove this model (Hissom transition) out as we go along, we can reduce some of this cost."

Costs to care for clients in the community are less than for institutional care, mental retardation experts said. Life in the community is infinitely better. Institutional care segregates and denies people opportunities for growth in all aspects of life.

Gerald Provencal of the Michigan Department of Mental Health gave expert testimony in the Hissom case. Today, no child in Michigan lives in an institution.

"If they can't be in their own homes, with supports, they need to be in foster homes," Provencal said. "Foster mothers make the foods they like. People don't get better because your mother gives you chicken soup, but because your mother rocks you and thinks you're the greatest thing since sliced bread."

"So many people have said this is the right thing, that it's a simple thing," said Pat Wear, executive director of the Homeward Bound Review Panel. The panel oversees the transition of Hissom clients.

"This is a major undertaking," he said. "There are no simple road maps to follow. I think people have unrealistic expectations about how well it should be going."

Although costs of moving clients into the community were not supposed to exceed costs of institutional care for the average client, costs have more than doubled.

Misconceptions need to be addressed. Legislators don't understand what this is all about, Wear said, adding that he doesn't mean that in a derogatory manner.

"It means more than dollars and cents. It is the right thing to do."

Evidence of that is abundant. For many clients moved into community settings, their lives have been enriched. They experience rights and freedoms denied at Hissom. Some with severe disabilities have made dramatic improvements. Others with lesser disabilities have had few difficulties and appear to be thriving, working and paying taxes.

Tulsa Mary Ann Duncan's foster son has emotional problems and severe mental retardation. At Hissom, Duncan was given a long list of things her son would never be able to do. He's in the community now, participating in a program that allows job sampling.

Duncan's foster daughter has been out of Hissom 1 1/2 years. She is multi-handicapped and profoundly retarded. She has doubled the self-care things she can do, Duncan said.

"A month before she left, her attention span was so short Hissom decided there was no purpose for her to be in therapy," Duncan said. "Now, she dresses and undresses herself." Recently, she did her laundry without being reminded.

"They said she couldn't be helped — she's hopeless."

Not all parents of Hissom clients agree with the move to community care. Tulsa La Moine Fuller fears for his daughter's safety.

"Shoving them out into an abusive society and expecting a cold-blooded, fly-by-night, corporate entity to care for their needs will never succeed," Fuller told U.S. District Judge James O. Ellison, who presided over the Hissom case. "It will be their demise."

Fuller doesn't believe provider agencies the state has hired will provide the care needed. Closing Hissom is "just absurd — really. But, the word institution in this day and time has become a dirty word. That's unfortunate."

The most important thing about the program is the increase in independence, "clients learning to meet their own needs," said attorney Louis Bullock, whose suit resulted in the court order.

That allows tremendous benefits for everyone, Bullock said.

"For the individual, it means increased pride. You can look forward to people who take pride in themselves gaining further independence for life," he said.

"For society, not only do you get a contributing member, but that's one less burden that falls on the state. People are graduating from schools and people are learning basic self-help skills around their homes."

As the state tries to cope, Bullock has threatened to sue again. Oklahoma has failed to expand deinstitutionalization to other institutions and to nursing homes.

Demps said he has no idea what it's going to take to deal with other institutions and the rest of the state.

"We're going to be working on that constantly," he said. "I don't want to end up in court, either."

Approximately 90,000 people with developmental disabilities and mental retardation live in Oklahoma. The state is helping no more than 6,000 at any one time.

Those people could be helped, Bullock said. Present programs would be "far more cost effective" if the state would allow access to non-Hissom class members.

"Hissom class member programs are expensive because we've only offered programs to class members. The rest of the system is trying to find ways to feed out of that same trough."

As long as the state focuses on Hissom, it's not going to get anywhere, Demps said.

"We're living in the past. Start-up costs were high, and, yes, there were mistakes and the audits catch those," Demps said. "But let's look at public policy for where we want to go ... stop looking back."

Nurtured in Vian, Renee blossoms



SANDY RONK doesn't regret her decision not to place son Jeremy, on the sofa, in Hissom. But the Tulsa teacher has a hard time coping since giving birth to Michael, who like his brother has severe developmental disabilities.

By **DONNA HALES**
and **KRISTI FRY**

Phoenix Staff Writers

VIAN — Cockroaches no longer crawl in 10-year-old Renee Parker's ears.

The multi-handicapped youngster began crying in November 1987 and hitting her ears. They were severely infected — with a dead cockroach decomposing in her left ear.

That was part of the testimony that convinced a federal judge to order the closing of Hissom Memorial Center in Sand Springs, Renee's home since age 4. All residents of the home for people with developmental disabilities are being moved into the community by October 1994.

Former Hissom Superintendent Dr. Julia Teska testified it was not unusual

for cockroaches to crawl on residents.

U.S. District Judge James Ellison found that Hissom residents were subjected to outbreaks of shigella, salmonella, influenza, hepatitis, lice, rashes and gonorrhea. Medical record keeping was grossly inadequate.

Accidents and abuse were prevalent at Hissom, according to the state's own records. There simply wasn't adequate staffing to care for the clients who lived at Hissom, Teska said.

Renee's parents gave her up at birth.

She was born with an enlarged heart and upper respiratory problems, and was diagnosed as having cytomegalovirus infection, known as -CMV, a debilitating herpes virus.

Renee also was diagnosed as profoundly retarded, non-verbal, blind and deaf.

Renee moved into a foster home in March.

She is now with loving parents, A.T. and Miriam Jett of Vian. She is flourishing under the care she receives. She is a member of an elite group of former Hissom residents — one of six clients enrolled in what is known as "the model program."

The state purchased a customized van, which is at Renee's disposal. She has 24-hour care from health aides except on the weekends when A.T. Jett is available to help more.

Miriam Jett said if she didn't have the full-time aides to help her, "I couldn't make it. I just don't see how I could."

Renee is provided a speech therapist to help with oral motor skills. Now, she is (See LOVE on Page 4)

Love, support turn Renee's life around



Staff photo by Kristi Fri

THERAPY IS MORE fun for Renee Parker with a little support from foster mother Miriam Jett. A.J. and Miriam Jett rescued her from a life of institutional care at Hissom Memorial Center.

(Continued from Page 1)

fed through a tube in her stomach. It is hoped she will learn to chew so she can be fed by mouth. She also is serviced by an occupational therapist and a physical therapist.

The model program was ordered by the court to serve as an example of what people with developmental disabilities can accomplish with support.

Renee can make noises, even though she can't talk. Miriam Jett is at her beck and call, praising her slightest movement.

"Come on — come on. Yeah! Renee held her hands over her head," Miriam Jett said, hugging her. "I love it."

"When you see someone making changes like she has in just a short amount of time, I guess you just look for unearthly things to happen."

Renee has four small, square board blocks covered with different materials. Her hands are placed on them to denote different things — riding in the van or going to the restroom, for example. It is hoped that Renee will pick up the right block to communicate someday.

The regimen at the Jetts has been good for Renee, according to her model plan case manager, Rachel Friedman.

"She's vocalizing, moving so much more, moving her arms a lot," Friedman said.

"Her's a good girl," Miriam Jett said, patting Renee. "Her's my girl. Her is so precious."

On June 15, Renee turned over from her left side to her back. Her records indicate she had never turned over before, Miriam Jett said.

"We just about had a spell," she said. "And she did it twice for me yesterday."

Miriam Jett is a hugger — a smiler — who shows genuine concern with every word and gesture. The Jetts have raised four children and have nine grandchildren. A 5-year-old granddaughter, Regina, lives across the street and helps see that Renee doesn't lack for attention.

Miriam Jett laughed as she recalled the youngster catering to Renee while Jett was talking on the telephone.

"I'm kissing her, Nana. I'm loving her," Regina hollered to her grandmother.

The Jetts cared for foster children when their children were growing up. Later, they managed a 24-resident home for the elderly in California. After moving back to Oklahoma, they decided they again could make a difference in a child's life.

They visited Renee at Hissom for a year before she was moved into their home.

She attends school and children crowd around her and argue about who will push her wheelchair.

"They take turns — draw names for which friend gets to bring her in so there's not a big fight every day," A.T. Jett said.

The couple had never been convinced that Renee couldn't hear or see. She was always so receptive to them.

Renee began crying at school one day and she was brought home. Baby teeth started to hurt her as other teeth were trying to come through. She was clenching her teeth. She had calmed down by the time Miriam Jett got her home. When A. T. Jett was told of the problem, he began crying.

"And then Renee got it in gear and started crying again," Miriam Jett said.

A trip to the ophthalmologist in June confirmed what the Jetts had believed all along — Renee can see.

Individual attention has paid off for Renee.

Until you give people individual attention, you do not know them and you do not know their potential, said Louis Bullock, attorney for the plaintiffs in the Hissom suit.

People who have a difficult time communicating are completely lost in the confusion and chaos of a large institution, he said.

"As a result, they just become isolated. It's a result of institutional environment — and that's not a flaw that can be fixed.

"Renee being able to see is a graphic example. They had written her off."

Outsiders grab contracts

By **DONNA HALES**
and **KRISTI FRY**
Phoenix Staff Writers

In ordering Hissom Memorial Center closed, U.S. District Judge James O. Ellison opened the floodgates for taxpayer dollars to pour out of Oklahoma.

Millions of dollars are being paid to lucrative private firms, mental retardation experts and others — with little or no state oversight.

Two companies — Therapeutic Concepts Inc. (TCI) and Progressive Therapeutic Technologies (PTT) — were paid \$11.3 million in consulting fees and expenses from 1987, when the court order was put into effect, through March 1991.

TCI, based in Winter Park, Fla., provides medical and technical consultants who train staff and perform assessments of Hissom clients. PTT, formerly based in Florida and now in charge of physical therapy at Hissom, designs and manufactures wheelchairs and adaptive equipment for Hissom clients.

Such fees have contributed to the astronomical \$190 million cost paid so far to upgrade services at Hissom and commence mainstreaming Hissom class members into the community.

Oklahoma firms and professionals got very little of that money. Nor did non-profit state organizations, long depended upon for building and operating group homes that serve Oklahoma's mentally retarded population.

Of 29 contracts let to build group homes in Oklahoma last year, 17 went to out-of-state companies.

Decisions on which firms got contracts were made by DHS committees with no uniform requirements and no written criteria for proposals submitted.

"There's no way I could see how they judged who they gave them to," said Effie Foster of Tah-

lequah, former president of Oklahoma Community Based Providers Inc. "You wrote a proposal and went up and defended your proposal.

"The people in Oklahoma felt like they were not receiving the same consideration other folks were getting. The premise seemed to be that existing programs were not as qualified."

Marie Skaggs, executive director of the Muskogee Association for Retarded Citizens, felt some out-of-state firms weren't qualified.

Central State Community Services Inc. of Midland, Mich., received five group home contracts in four Oklahoma counties.

Rae Tremble, executive director of Oklahoma operations for Central State, sought technical help from MARC in writing a policy and procedures manual.

"She said she had worked in direct care but had not been in management before," Skaggs said. "It really puzzles me."

But even more puzzling is how Tremble can supervise Central State homes across the state from a Tulsa office and be monitored by a home office in Michigan, Skaggs said.

"I find it a challenge to monitor a program as it should be monitored with a strong local agency. I live here in town and I'm on call 24 hours a day. I can't even fathom managing from that distance."

Skaggs finally offered to give Tremble technical assistance in writing the manual Central State needed, for a fee. Tremble told her the firm wouldn't pay such a fee.

Central State also received a \$387,442 program development

grant as a supported living provider for Hissom clients.

The firm's auditor says money from the restricted grant transferred to Central State's unauthorized administration fund may have "violated certain of the restrictive provisions of the related grants."

State Sens. Herb Rozell, D-Tahlequah, and Lewis Long, D-Glenpool, co-authored a bill calling for an investigation of excessive costs in the Hissom case.

Rozell questions, bringing in companies to help facilitate moving people into the community.

"The companies could have had them out, but why would they put them out if they could rake in the dollars and do it very slowly. A lot of legislators feel like these people were taking the money that actually goes to these mental retardation programs."

Fees for consultants who work for TCI range from \$250 to \$600 a (See CONTRACT on Page 7)

Contract funds flow out of Oklahoma

(Continued from Page 1)

day, plus expenses. All bills for TCI and its consultants — office space, equipment, local lodging, rental cars, air fare home to distant states on weekends — are paid by DHS, by court order.

TCI and PTT, in addition, charge a 10 percent management fee. For example: PTT pays a \$3,000 sign-on bonus to attract physical therapists at Hissom. Each time a therapist is hired, PTT collects \$300.

The reason out-of-state experts are in Oklahoma is because the state had a critical shortage of medical and technical expertise in mental retardation at the time of Hissom lawsuit. Ellison deled the state recruit expert IS said it had been unable to attract enough physical therapists. O say PTT was spending too much money for PTs, we were-said Charlie Waters, DHS general counsel. "We didn't have

Louis Bullock, attorney for the plaintiffs, contends DHS had ample opportunity to contract with PTT before the court ordered the state to use PTT's services and pay all expenses.

"If they had done it then, when they weren't being ordered to do it, they could have struck a better deal," Bullock said. "Instead, they waited until their backs were against the wall. The state just chose to put itself in a bad bargaining position and it is paying for that."

Even though DHS auditors have ruled the 10 percent management fee charged by PTT and TCI is not a legal expenditure, DHS continues to pay it.

TCI benefits in addition to direct fees it bills the state. Tim Greusel, one of five TCI partners and Oklahoma project manager, said TCI trains Oklahomans as consultants and trainers at taxpayer expense, then uses those people on other cases in other states.

Escalated consulting firm salaries run up costs. For example, a nurse working for a Tulsa organization earned \$23,000 a year. She went to work for TCI as a consultant and now makes \$300 a day.

DHS also was ordered to pay for monitoring and a model plan.

DHS also was ordered to pay for monitoring and a model plan.

David Powell, of Lincoln, Neb., at the time, was appointed by Judge Ellison as court monitor — as the judge's "eyes and ears" in overseeing DHS compliance with the Hissom settlement agreement.

Powell designed the model plan for seven Hissom clients. The plan was intended to show the state how to make the transition of clients living in institutions to living in the community. The state was billed more than \$2 million for model plan expenses.

Powell's fee as court monitor was \$72,000 a year, plus expenses. Now, he gets \$500 a day while in Oklahoma as administrator of the model plan. He gets \$75 an hour when out of state and working on

model plan business.

Feeling threatened by the court order, the state sat back, watched the bills roll in from these out-of-state experts, and signed the checks. No one — not the Department of Human Services, not the court-appointed monitor, not the federal judge himself — challenged invoices prior to payment.

A number of consulting charges on the court monitor's bill, for example, did not have time sheets or any type of documentation showing dates and times worked and name of client served, a DHS audit stated.

The audit, released in April 1991, also questioned payment in February 1990 of \$97.32 for personal phone bills and toys. The name of the person reimbursed through PTT was listed on the audit as "Cardogno." Cathy and Kay Cardogno are former partners in PTT who left the firm in early 1989, but do consulting work occasionally, a secretary to PTT owner Lee Phillips, Virilyaih Davis, confirmed.

The audit reflected a sampling of expenditures for four months.

Recoveries as a result of the audit have been minimal.

Legislative leaders tended to blame high costs and lack of fiscal oversight on Eranell McIntosh Wilson, hired in 1988 as administrator of DHS's Developmental Disabilities Services Division. She had been instrumental in the closing of institutions in Michigan and Alabama.

Rozell said former DHS Director

Phil Watson and Deputy Director George Miller were sold on Wilson.

"There was this feeling she was their protector from the federal government, because they really did uphold her in what she was doing," Rozell said.

Kirby Schnell, a parent advocate, wrote Oklahoma Community Based Providers Inc. about Wilson's power over DHS officials.

"The director (Watson) and deputy director (Miller) are mere buffoons without the common sense or the backbone to oppose someone as strong willed as the DDSD administrator," Schnell wrote. "As a result, they have become her unwitting allies and supporters in most of her endeavors to totally rewrite the state programs for developmentally disabled clients."

Wilson said judgments from damage suits always are more than would be if only those people had done what they should have in the first place.

Powell said consultants are cheaper in the long run than hiring people and paying benefits. He said he has no apologies for being one or commanding high daily rates.

"What's wrong with that — if I want to define my profession as taking a chance that somebody will ask me to work and not settling into a full-time job any one place?" Powell said. "I'm not stirring up these problems. I'm out there helping solve them at somebody's else's request."

Select few leave little for others

By KRISTI FRY and
DONNA HALES

Phoenix Staff Writers

This is a story about the haves and the have-nots among people with developmental disabilities and mental retardation in Oklahoma.

The haves: 1,077 class members of Hissom Memorial Center, an intermediate care facility for the mentally retarded (ICF-MR) in Sand Springs.

The have-nots: 2,524 people in other private and state ICF-MRs; 576 people who have applied for

services, qualify for them and are stuck on waiting lists; about 1,800 people with mental retardation in nursing homes around the state; and thousands more, but state officials don't know who they are or where they are. They just know that demographics indicate there are 3 percent, or approximately 90,000 people with developmental disabilities in Oklahoma.

"I don't think we have a very clear idea of what the need is. If you don't do anything for people, they tend not to come forward,"

said Jim Nicholson, interim director of the Developmental Disabilities Services Division of the state Department of Human Services.

"There are 6,000, tops, in the delivery system at any one time," he said.

Why the inequities?

The haves got their slices of the pie when a federal judge ordered DHS to close Hissom and move its clients into a community-based system of care by 1994. But Oklahoma didn't have a community service system. It has had to build the system as it places clients, a slow and costly endeavor: three years and more than \$190 million so far.

The have-nots are being told they can't have their slices of the pie because Hissom clients have scooped them all up.

"The department is committed to the mentally retarded population of Oklahoma and is moving in that direction — wholeheartedly committed," Nicholson said. "But, it's going to take some time."

The have-nots and their advocates are beginning to lose patience, a three-month investigation by the Muskogee Phoenix reveals.

"We are dead set on seeing this care extended to everyone throughout the state who needs it," said Louis Bullock, attorney for the plaintiffs in the Homeward Bound vs. Hissom lawsuit. "If the state doesn't begin to expand it, then we're going to go after Enid and Pauls Valley (state schools for the mentally retarded). We're also going to go after the nursing homes."

Families of children and adults in need don't understand. They claim it isn't fair to help a select few while their needs go unmet.

Patty Hendrickson's sister, Rae Marie Grimes, 35 and autistic since birth, spent her life living with her parents in Muskogee. Rae Marie had to be placed in a small ICF-MR when their parents died last year. The transition was dev-

(See RESOURCES on Page 8)

Resources go to state's select few

(Continued from Page 2)

astating, her sister said.

Rae Marie was a big woman, unable to speak but very capable of living with some support, Hendrickson said. She contracted trench mouth in the ICF-MR and, within six months, her dress size shrank from a woman's 22 1/2 to a child's size 14. Hendrickson removed Rae Marie from that "place for forgotten people." Rae Marie now lives in another ICF-MR. She is digressing in function and weighs 92 pounds.

Rae Marie comprehends what is happening in her life and is hurting, Hendrickson said. Hendrickson is hurting, too.

"I love her, but I can't do what Mom and Dad did. I can't make that sacrifice. I'm just not willing. It's like having a baby forever," Hendrickson said. "I just can't do it. I feel real guilty about it."

She's had to weigh the needs of her three sons, family life and her ability to work outside the home.

"So, I go see her a lot," Hendrickson said. "It's a sad deal for people like that. You either put them away and feel bad about it or put them away anyway and feel guilty."

Hendrickson said her sister would be happier in a supported-living arrangement with a roommate and some supervision, an option now being offered to Hissom class members. Rae Marie is not a Hissom class member.

"She's had a whole lot better than that, that makes it hard for us, too, knowing that she knows . . . she wants to get out of that hell hole."

Rae Marie's mother, Mary Frances Grimes, *wanted out, too.*

She had a tough time coping after the April 1990 death of her husband of 48 years. He had been closest to their autistic daughter. Mary Frances Grimes contracted pneumonia, and died of kidney failure. Her illness shouldn't have been fatal, Hendrickson said.

Carolyn Crawford of Tulsa, Hendrickson's sister and Rae Marie's guardian, agreed.

"She willed herself to die," Crawford said. "Daddy spoiled Mama really bad. She would sit on his bed before he died and cry."

She didn't have the strength or will to go home and care for Rae Marie by herself.

"She wanted to die," Hendrickson said. "And, none of us were enough to keep her from it."

Cheryl and Gary Crossland of Muskogee feel cheated. They chose to keep their son, Jarrett, 10, who has developmental disabilities and a seizure disorder, in their home with their two other sons, Nick, 12, and Eric, 2. They sought help from the state when Jarrett was 2, but were told their income was too high, Cheryl Crossland said.

"We get frustrated because we feel like if we would put him in one of those homes or nursing homes, everything would be totally paid for," she said. "Sometimes, we feel we are being penalized for keeping him with us."

Jarrett requires a lot of attention, and a lot of money.

The Crosslands must rush him to the emergency room from time to time. Seizures have become more severe the older he gets. Even with health insurance, a \$10,000 pile of medical bills haunts the couple.

"They don't understand. You may have 15 different bills from radiology and before you get through, you're getting them from everybody."

There are other expenses: diapers are \$60 a month. Jarrett needs a standing frame so his mother can work on his legs. The cost: more than \$500. His wheelchair, \$3,000, was modified to lower the level of his feet, \$350.

Other chores: changing diapers, feeding, lifting him in and out of his wheelchair, medications.

"I don't expect them to pay his way," Cheryl Crossland said. "But, if there are other kids out there getting it, then he deserves it, too — just as much."

"They're doing exactly what we want them to do," Bullock said, and they aren't getting any help. "That's right, and in fact one of the things that caused the folks to go to Hissom in the first place was the fact that the state didn't spend the money to support the people in their homes."

They loved the little gal' at Hissom, father says

By **DONNA HALES**
and **KRISTI FRY**

Phoenix Staff Writers

Les Baxter was so terrified his healthy daughter would be afraid to have children, he kept her from seeing her twin sister for 28 years.

The sister, Shelly, was born with severe mental retardation.

Baxter and his wife took both daughters home from the hospital after they were born in 1960. The Baxters struggled to help Shelly, born with Down's syndrome and a heart condition. But Shelly was confined to bed for most of the first three years of her life.

They had the other twin and three older sons to care for, too.

On advice from professionals, the Baxters placed Shelly in Hissom Memorial Center at Sand Springs in 1964.

"It's the first time I ever cried," Baxter said. "Grown men aren't supposed to cry."

The ordeal took its toll on Baxter's wife, Bonnie. She turned to alcohol to cope and died earlier than she should have, he said.

Shelly, now 31, has remained at Hissom, well cared for and loved, her father said. Her twin sister, Sherry, grew up, married and had two healthy children.

Professionals told Baxter that people with Down's syndrome, especially those with respiratory and heart problems, rarely live past their teens. When Shelly dies, Baxter will take her to a cemetery in Kansas and bury her beside her mother.

That's when Sherry will "see

Shelly for the first time," he said.

Baxter, an Oklahoma City businessman, never second-guessed placing Shelly in Hissom. He hasn't changed his mind. Whenever he checked on Shelly's well being at Hissom, he never found things amiss.

"I feel my daughter, for the last 28 years, has been cared for very well. The individuals who cared for her — they actually loved the little gal."

Now, the state is telling him Shelly can be better cared for in a house in the community with round-the-clock habilitation aides watching over her.

Mental retardation experts told U.S. District Judge James O. Ellison of Tulsa the same thing about all Hissom clients. A group of parents with children in Hissom sued to close the institution in 1985. Ellison ordered Hissom clients placed in community living and the institution closed by October 1994.

Baxter doesn't understand the logic behind the move to supported living.

It's a "damn fool judgment," he said.

The most recent report on Shelly mailed to Baxter is voluminous — 123 pages. Throughout, the report states her mental age is under 11 months. The report was prepared by an interdisciplinary team, a group of about 16 professionals and others who decide what's the least restrictive environment for (See DAD on Page 5)

Dad doesn't see logic in court order

(Continued from Page 2)

Shelly and what her needs will be.

"Reams of paper are prepared, which are repetitive and basically redundant," Baxter told Department of Human Services Director Benjamin Demps Jr. in a recent letter.

Baxter has been told Shelly's annual budget is \$136,000.

"According to the report, she's going to have to be employed 10 hours a week," Baxter said.

Shelly was informed of her rights. She displayed neither interest nor understanding, according to the report, an Individual Habilitation Plan.

Shelly attends vocational training two hours a day. A goal is to increase that to four hours a day.

"How you can hire somebody and justify paying so-called professionals to help Shelly develop a vocation, I cannot understand," Baxter told Demps.

Shelly's August 1990 habilitation plan includes giving her voting information and locating her polling place.

"It's just unbelievable," Baxter said.

The team's plan for Shelly calls for a \$23-an-hour employment specialist and the part-time job for Shelly.

"They told me she could sort colors. Now, who's going to pay for that?" Baxter said, shaking his head.

Shelly is non-verbal, but makes noises. She was assigned a \$20-an-hour speech therapist.

"She can walk 50 feet if you start her and stop her," Baxter said. "She can't converse, can't take care of bodily functions and eats pureed food."

A lot of people with Down's syndrome can work, but Shelly can't, Baxter said.

The professional report on Shelly contains these requests:

- A habilitation training specialist at \$8 an hour for 2,190 hours, or \$17,520 from August 1990 to August 1991.

- An occupational therapist.
- A psychologist.
- A speech therapist.
- A nutritionist.

"All these analysts — the average income of that group of people has to be at least \$50,000," Baxter said. It appears DHS has "a fairly large group of professionals that are sucking the citizens of Oklahoma dry."

He attended the first meeting regarding a community placement plan for Shelly about 18 months ago in Oklahoma City.

"Eventually, my daughter and about 16 people showed up," Baxter said.

He was told Shelly had been out looking for a house.

Someone told him they had looked at three houses — and that Shelly picked one out in Bethany. It was a three-bedroom home with a fenced back yard and a patio. Baxter asked how anyone could tell that Shelly picked out the house.

"Oh, we know," he was told. "She will be involved in community affairs, and if she wants to, she can go to church."

"I asked them, 'Does she know about Jesus?' Well, Jesus knows about her," he said.

Baxter drove by the house in Bethany, but it was empty for more than nine months.

"I've always been interested in who owned it," Baxter said. "Furniture was put in it."

Shelly never moved there. Her interdisciplinary team decided it would be better if she were allowed to live with her oldest and dearest friend of choice in Muskogee. Shelly's friend moved into the home in early 1991. But before Shelly moved in, her friend died. In April 1991, Shelly moved into the house.

"Going out and renting that home is asinine," Baxter said. "I don't think they need all of these consultants."

Baxter believes Shelly and Oklahoma taxpayers are being exploited. Shelly could be moved into a smaller facility than Hissom, he said.

"I'm for taking care of people, but I'm not for throwing money away," Baxter said. "I'd rather see her adequately cared for and the rest of that money going to help other people."

Every time he tries to object, he's told the plan is a result of Judge Ellison's order.

"They act like this was God's edict, so this is what we're going to do. There's no feedback. There's just no common sense to it. They keep saying they want parents to have input. They keep acting like it, but..."

"It's the biggest waste of taxpayer money I've ever seen."

Struggle strains a mother's love

With 2 in need, little help, family feels cheated

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

Shoving Robby in his wheelchair up two wooden ramps, Molly Gregory falters. In a split second, the front wheels twist and the chair turns. Molly braces against the chair and hangs on.

Like a weightlifter straining, Molly focuses her concentration on the task and regains control. Her large frame prevents her 17-year-old son, who has cerebral palsy, from tumbling to the ground.

Molly's struggle to load Robby into the family van places both of them in jeopardy, Molly said. She's dropped Robby before. That worries her. Her daughter, Amanda, 6, also has cerebral palsy. Amanda must be rolled into the van, too.

Lots of things worry Molly Gregory, 45, lately. She worries that her son Scotty, 12 and healthy, is being robbed of his childhood because he devotes so much time to his brother and sister. She worries about Robby losing too much weight; and that even though Amanda can stand with braces, the family can't afford to buy them. She worries whether she can keep going, keep coping day in and day out.

The special education director and assistant principal at Mannford Public Schools thought she could take anything.

"But I got to a point when it was time for school to be out and time for me to come home for the summer, I didn't want to come home. And I love them," she said, her voice cracking, tears swelling in her eyes.

"I love them more than I can ever say. But my job is kind of my refuge, I guess. It's kind of that way for my husband, too."

Molly told her doctor she didn't know what was wrong. Her husband, Robert — "the best daddy in the whole world" — is always there to support her. But both juggle jobs while providing 24-hour care to their seriously ill children.

"I just want to cry. I want to run off. I want custody to go some place where we don't have to deal with all this," she told her doctor. He gave her something for depression.

"It helps, but it seems like each year as you get older . . . there's the fact that Robert and I can't go anywhere — we can't do anything. Our whole life is right here."

The Oklahoma Department of Human Services provides some services for Robby. But because of a federal court order to close Hissom Memorial Center, those services have been reduced and may be cut altogether, Molly said. Amanda has been on a waiting list for services. DHS confirmed) she receives no services.

The Gregorys, typical of hundreds of Oklahomans who I have children with developmental disabilities, feel cheated. The read and hear about all the money being spent to place Hissom clients into the community and they don't understand why their children can't receive similar services.

We need the same help, Molly said. "I almost think we ought to get it before them because we kept our kids here. We're bearing most of the financial part of it. We're taking care of that."

Robby and Amanda have needs that go unmet:

- A lift for the van.

- New wheelchairs. Robby and Amanda spend much of their time in wheelchairs that are worn out and too small.

Robby was evaluated for a new wheelchair that the Gregorys believed DHS planned to purchase. The Gregorys paid \$300 for the evaluation. DHS told them the paperwork was lost and because of the Hissom order, the agency couldn't pay for the chair anyway, Molly said.

DHS contends there was a problem over where the wheelchair was to be purchased. The matter is unresolved.

- Robby's DHS case manager, who the Gregorys felt worked well with Robby and the family, is no longer assigned to him. Her replacement is inexperienced, Molly said.



AMANDA GREGORY, 6, responds to her mother, Molly Gregory, with affection, interest. Amanda's too big for the worn-out wheelchair.

"They change in the middle of the stream. It's all lost and somebody has to start all over."

DHS said the case manager is new to the Oklahoma system, but has had similar experience in Arkansas.

DHS provides Robby with physical therapy and a habilitation aide for at least five days a week. That person is not permitted to administer medications. So if the Gregorys take Amanda and Scotty out, they cannot be gone long.

"We're told if they needed the person taking care of Robby now (for a Hisson client), we would not have that person," Molly said.

■ The family's only bathroom presents a back-breaking obstacle. Robby's wheelchair won't fit and he must be carried in and out.

Robby weighs 72 pounds.

DHS sent someone to evaluate the room for remodeling. That evaluation is lost now, too, Molly said.

DHS said the evaluation has not been lost. "The case manager is proceeding with the process to make the bathroom accessible to all family members," said Leslie Yaryan, DHS district supervisor.

"When are they going to do that?" Molly asked. "How long is that going to be on the desk?"

"It's like they bring everything up to you and you think you're finally going to get some help to make life a little bit easier . . . and something just closes the door. You just get to where it doesn't look like it's worth it sometimes."

■ Plastic bracing for Amanda's feet and ankles. Her first pair cost nearly \$1,000. She has outgrown them.

■ More therapy for Robby and Amanda, including a communications device that Molly feels would prevent Amanda from being "trapped in her own little world" like Robby is.

Robert Gregory, 46, a mechanic at a Tulsa car dealership, worries, too. But he stays too busy to get depressed, he said.

"I probably would have given up a long time ago, but he never will," Molly said. "These kids are his whole world. He's going to see these kids are taken care of."

Robert has built ramps for their cramped three-bedroom Tulsa home. He made the ramps to load the kids in the van. He makes toys activated by switches for Robby and Amanda. He's working on a race car set right now.

His positive outlook on life, however, is constantly under fire. He has trained himself to wake up every two hours during the night because Robby, who has severe seizures, cannot turn in his bed and could choke and strangle. In addition, Robby requires little sleep.

"He could just go 24 hours — and that just tears a family apart," Molly said. "Sometimes, we take him out on the front porch and rock him."

That keeps him from waking the other kids. His bed is at one end of the kitchen and next to the children's bedrooms.

Robby's medicine costs run as much as \$200 a month. The Gregorys have health insurance, but must pay all health expenses up front. After deductibles are met, there's a long wait for 80 percent reimbursement "and they question everything we do," Molly said.

Cerebral palsy results from damage to the brain before or during birth. Robby and Amanda are spastic, but Robby's spasticity is worse. Neither can speak, nor sign.

"The only way we have for them to tell us something is wrong — they'll cry," Molly said, tears rolling down her cheeks.

Nothing is easy.

The children must be dressed and bathed. Their food must be cooked, pureed in a blender and spoon fed. Both are prone to choking while eating. Their diapers must be changed four or five times a day, which requires lifting the children out of their wheelchairs and then back again. Medications must be given. Activities for all three children must be arranged.

That's why Molly Gregory worries. That's why sometimes — after the state dangles the carrot, then runs and hides — Molly's frustration and guilt overwhelm her.



Molly Gregory

Staff photos by Kristi Fry

IT'S A RISKY and laborious chore, but Molly Gregory must push son Robby, 17, up a homemade ramp and into a van daily at their home in Tulsa. Habilitation training aide Brenda Petty looks on. (Story, Page 2.)

► THE TAB: \$190.1 MILLION

Hissom related costs

	Fiscal 1987	Fiscal 1988	Fiscal 1989	Fiscal 1990	Fiscal 1991 through 3-31-91	Total amount
Direct expenditures	\$ 18,383,904.00	\$ 20,875,452.00	\$ 26,026,246.00	\$ 30,547,541.00	\$ 22,087,709.00	\$117,920,852.00
Administrative costs	1,245,594.00	1,497,061.00	2,223,096.00	2,461,940.00	2,123,423.00	9,551,114.00
Plus PTT* and TCI** (paid through court clerk)	874,276.00	1,854,132.00	2,512,882.00	3,189,637.00	2,881,141.00	11,312,068.00
Total - Hissom operations	20,503,774.00	24,226,645.00	30,762,224.00	36,199,118.00	27,092,273.00	138,784,034.00
Plus other "Homeward Bound" costs (paid through court clerk)	419,270.00	402,024.00	1,324,769.00	1,850,358.00	1,421,511.00	5,417,932.00
Plus legal fees and other miscellaneous costs ¹	2,250.00	403,851.00	418,096.00	365,264.00	813,336.00	2,002,797.00
Community services' costs related to class members ²	-	-	674,373.31	7,280,821.56	10,564,373.04	18,519,567.91
Department of Human Services legal expenditures ³	-	335,600.00	222,900.00	177,700.00	26,400.00	762,600.00
Case management/assessment	1,150,794.00	1,614,547.00	6,039,226.00	8,800,571.00	7,018,811.00	24,623,949.00
Class members receiving community services during FY	NA	NA	NA	131	205	-
Grand total	\$22,076,088.00	\$26,982,667.00	\$39,441,588.31	\$54,673,832.56	\$46,936,704.04	\$190,110,879.91

Clients at Hissom

Census as of June 30 ⁴	441	424	404	336	-	-
Census as of March 31, 1991	-	-	-	-	290	-
Hissom per diem	\$129.39	\$157.71	\$215.42	\$276.86	-	-

Current average daily cost per supported living client is \$225 (based on amount obligated by contract. This does not include cost of vocational services).

* Progressive Therapeutic Technology, provides physical therapy services, designs and manufactures adaptive equipment for Hissom clients.

** Therapeutic Concepts Inc., a Florida-based firm providing medical and technical consultants for staff training and some client assessments.

1 - Paid through Hissom Memorial Center account

2 - Supported living (rent, phones, utilities, furnishings, etc.), supported employment, community integrated employment, waiver services.

3 - Covington and Burling, Washington, D.C. law firm

4 - End of fiscal year

What firms bill, DHS blindly pays

\$11.3 million-plus spent with little documentation

By **DONNA HALES** and
KRISTI FRY

Phoenix Staff Writers

OKLAHOMA CITY — The state paid \$38.8 million between 1986 and March 1991 to mostly out-of-state vendors and professionals in connection with the court-ordered closing of Hissom Memorial Center.

More than \$11.3 million was paid to two out-of-state companies hired by order of the court to help facilitate closing the Sand Springs institution for the mentally retarded.

Little or no documentation accompanied billings from those two firms, a three-month investigation by the Muskogee Phoenix revealed.

In all, Hissom-related costs from July 1986 through March 1991, including running the institution and hiring case managers for clients: \$190.1 million, according to DHS figures obtained by the Phoenix.

Only since March have DHS administrators questioned invoices before payment, even though for two years DHS auditors cited questionable expenses for everything from pet air fare to more than \$1 million in management fees paid the two firms. Neither firm has authorization to bill DHS a 10 percent management fee, according to DHS general counsel Charlie Waters.

Other examples of questionable costs:

- \$17,000 billed from a job order for goods not received.

- Ten 10-karat gold ball point pens, \$187.82.
- \$160 dinner for four.
- \$134.88 for an employee-client party.
- \$333.30 for Christmas cards.
- \$195.94 for pens bearing logos and names.

- More than \$4,000 for an electronic sweep of one of the main vendor's offices and apartments.

Payment of unreviewed expenses prompted new DHS Director Benjamin Demps Jr. to plan changes.

"Internally, I have to do some things," he said. "I have to adjust the organization so that I won't have unreviewed expenses. I won't have things going on that haven't been given management attention. That has to be done pretty swiftly."

The \$38.8 million is double a figure made public earlier. That figure didn't include more than \$19

million paid to providers servicing Hissom class clients living in the community or \$762,600 to Covington and Burling, a Washington, D.C., law firm representing DHS.

All expenses involved in that \$19 million have not been audited yet, said Bill Leitner, DHS public relations specialist.

Nothing was being hidden — the media had asked only for the court fund expenditures, said Jim Nicholson, interim director of the Developmental Disabilities Services Division of DHS.

Direct costs at the Sand Springs home for the mentally retarded have risen since 1987 to bring staffing and services into compliance. Population has dropped.

U.S. District Judge James O. Ellison ruled Hissom residents were being segregated, discriminated against and mistreated. He ordered residents be placed into the community and the institution be closed by October 1994.

The court fund tab to DHS includes payments to:

- Various attorneys of the plaintiffs — \$2,002,797, billings that were reviewed by the parties and the court.

- Progressive Therapeutic Technology (PTT) — \$6,436,377.86 (includes a 10 percent management fee). PTT provides physical therapy services and designs and manufactures adaptive equipment for Hissom clients.

- Therapeutic Concepts Inc. (TCI) — \$4,875,690.48 (includes a 10 percent management fee). The Florida-based firm provides medical and technical consultants for staff training and some client assessments.

- David Powell, former court monitor and now administrator of a model program consisting of six former Hissom clients — \$1,026,098.17 (includes model expenses).

- Bill Sagona, guardian ad litem — \$476,600.99 (he and staff represent more than 245 Hissom class clients who are wards of the state or whose parents don't actively participate in plans for their children).

- Judith A. Finn, Sagona's predecessor — \$525,509.76.

- Homeward Bound Review Panel — \$150,502.28

(expenses began in fiscal year 1991).

No one has accepted responsibility for failing to review the court fund invoices before payment.

Powell said he understood DHS had 10 days to examine his billing and make any objections.

"I don't know who was responsible, but I tell you it was next to never done," Powell said.

DHS has requested detail only since March, "when the politicians started asking questions," Powell said.

DHS attorney Waters agreed that documentation on billings wasn't checked before payment.

"Well, that's right. It's an after-the-fact look . . ." Waters said.



Demps



Powell

That was because someone needed to be paid, he said. He later said the bills were handled through standard procedures.

The legal division received the bills because a court communicates with a client through lawyers, Waters said.

"I'd be very much surprised if very many people saw the bills," Nicholson said. "If Phil Watson (former DHS director) saw a bill to take a dog to the vet, I think he would have reacted. I think he would have been outraged."

Court fund bills now are being reviewed elsewhere in DHS, Nicholson said. Bills from the model program are supposed to come through the administration unit — part of the division's response to the audit, Nicholson said.

If something can't be reconciled through the auditors and the program people, "then I think we have the green light from the court to bring it to the attention of the court," Waters said.

DHS had the green light all along. Ellison's orders addressed costs and ordered DHS to report any barriers in carrying out his orders.

"No one squeaks louder than Judge Ellison," said Louis Bullock, lead attorney for the plaintiffs. "The man is down right penurious."

A consent decree filed in early 1990 requires no more expenditures "on an average per-capita basis to maintain and serve clients in the community settings than is currently being spent to maintain and serve clients on an average per-capita basis at THMC (Hissom)."

The standard is to apply on an aggregate basis to expenditures for all clients, rather than on a case-by-case basis. A similar order governs the expenses of the model plan by its second year, stating that amount would be \$175 a day (\$63,875 annually). One model plan client's budget for 1991 is \$234,000.

Waters said one reason DHS didn't do more questioning of expenses it paid through the court fund was because it had a poor standing with the court.

Two years ago, the department had no credibility with the court, Nicholson said.

Waters cited "tremendous public clamor" after DHS failed to negotiate the suit in 1987 and later appealed the case to the U.S. 10th Circuit Court of Appeals.

"There were people for community services who thought the institutions stunk. And other people wanted us to fight the whole thing. So, while we're in this adversarial posture with what the court wants, we really didn't have a lot of credibility with the court."

Contempt proceedings were being threatened, he said.

"Now, I don't want to say that if we had found a large expenditure that was excessive or improper and brought it to the court's attention . . . I'm sure the court would have dealt with it appropriately."

DHS early on reneged on services promised in the time frame set out.

"It was an impossible task, and we had promised to crank out all these things," Nicholson said.

He said many people were overwhelmed with the amount of detailed stuff DHS agreed to do and that so little was connected with moving people out.

court record made in January 1988 by Phil Watson,

"We thought we could do something, and we didn't have it to do with," said Dan Broughton, DDSD liaison with the court parties.

Ellison clearly was not impressed with DHS efforts at the time. He appointed Powell court monitor in May 1988 to assure compliance with the court's order, saying, "Nothing in the defendants' actions has given this court the mere suggestion that compliance is intended."

Ellison placed comments in the

DHS director at the time, to Hissom employees.

Watson said it would be a tragedy if Hissom closed, that some things decreed by the court "are utterly ridiculous. In fact, legislators in Oklahoma City are thumbing their nose at the judge."

Watson told employees none had better admit Hissom should close. He said the war wasn't over, "not by a long shot . . . We'll stall 'em in court for years."

His speech enraged the superintendent of Hissom at the time, Dr. Julia Teska. She referred to it in her resignation letter to Watson four months later, a copy of which Ellison made a part of the court record.

Teska's allegations included:

- Watson and Covington and Burling had taken the position that "not only is conflict unavoidable but that it is desirable."

- It was impossible to get answers from the DHS legal division and calling it was "somewhat akin to calling 'Dial-a-Prayer for Atheists.'"

- Management, including Eranell McIntosh Wilson, the new DHS mental retardation and developmental disability expert, had advised it was time to "head 'em up and move 'em out" without choice of place ment.

- Support of Hissom programs was superficial at best.

- DHS abandoned a plan to develop a service delivery system with options for all citizens with mental retardation.

Teska's resignation followed the resignations of Dr. Jean Cooper, who had served as administrator of DDSD since 1983, and Mary Ann Overall of Tulsa, DDSD Area II manager and programs assistant administrator. They, too, contended DHS had abandoned its prior commitment to all citizens with mental retardation. Their resignations also became a part of the court file.

DHS credibility reached a new low.

Bullock said in a March 1989 court filing that if the placements out of Hissom were "a vision for the future of this delivery system, it will take over 70 years to move the clients presently residing at Hissom to community placements."

But Bullock is convinced that if DHS had asked questions about the billings before the audit, "they would have gotten answers that would have satisfied everybody and we would have ended up avoiding the appearance of scandal — which the scandal's a lot of smoke."



Advocate's experience with brother drives home his mission to clients

By **DONNA HALES**
and **KRISTI FRY**
Phoenix Staff Writers

SAND SPRINGS — Bill Sagona was still a teenager when his mother told him his brother, Barney, had died after being committed to a Florida institution at age 10.

He remembers Barney being toted around the house in a wooden crate on wheels. Barney was profoundly retarded and had epilepsy and physical deformities.

Sagona was 15 or 16 when his mother stifled his questions about his brother with the news that Barney had died.

Sagona eventually became a coordinator for a staff development institute. The institute was hired by the state of Florida to conduct training after Florida's four institutions for the mentally retarded were ordered closed in 1976.

Sagona always wondered how Barney died. One day, while visiting Orlando Sunland, one of the institutions where his brother had lived, he asked a social worker if she would check the records on his brother's death.

The social worker returned with startling news.

"Barney's not dead. He's here."

Today, Barney resides in a small house in Florida with seven other developmentally disabled people.

Sagona is working in Oklahoma as guardian ad litem for more than 245 mentally retarded people who are or who have been residents of Hissom Memorial Center. U.S. District Judge James O. Ellison has ordered Hissom closed by 1994 and all clients moved into the community.

Being guardian ad litem means Sagona is chief advocate for the 245 people. Most of those he serves are wards of the state or their parents have ceased to be actively involved in their lives.

Before being appointed to the job full time in February 1989, he served as program consultant and coordinator for the original guardian ad litem.

who had served on a part-time basis because of other employment.

Sagona knows firsthand what the profoundly retarded, even those with skeletal deformities, can accomplish. He keeps a picture of Barney in his office. His family had been told early on that Barney couldn't benefit from active treatment.

"Now, he can sit upright, swallow his own food, is aware, watches TV — has preferences," Sagona said. "He can manipulate knobs for the TV. He's in the world. And as far as I'm concerned, that's active treatment — anything that enhances basic skills a person has and anything that prevents future degeneration."

One of Sagona's appointed tasks is to try to reinvolve families in the lives of the people he serves. Ellison has ordered his advocacy be as minimal as necessary to be effective.

The guardian's office is represented on a team of professionals who decide on a plan for community placement of Hissom clients under his wing.

Most Hissom residents are adults. For the children in the institution, Sagona advocates supportive services in their own homes or foster home placement.

"It's different to have a mom than to have three shifts a day," Sagona said.

He and other professionals involved with the closing of Hissom say many clients who lived there never should have — that they were too capable to have been institutionalized.

Many had emotional problems that made them hard for families to manage and labeled them unacceptable in the community, he said.

On July 24, 1987, Ellison, in addressing his findings of fact after the state of Oklahoma requested a stay of his order to close Hissom, wrote that an "examination of the quality of life experienced by individuals residing in Hissom fails to show a single person who is benefiting from living in the institution."

That place that was so awful'

By DONNA HALES
and KRISTI FRY
Phoenix Staff Writers

SAND SPRINGS — They were dirty, with green teeth and long, untended fingernails.

They lived in units infested with cockroaches that crawled on their bodies because they were unable to brush them off. There were too few staff members to adequately care for them.

They ate from feeding bottles that were often filthy and caked with residue; as many as 50 at a time were placed in rooms and restrained in wheelchairs with nothing to do but stare at the walls.

They were abused, physically and sexually.

"They" were people with developmental disabilities who were placed in Hissom Memorial Center — human beings who were segregated, discriminated against and mistreated by the state of Oklahoma.

Staff stood "idly or chatting with one another" while clients engaged "in such behavior as stuffing twigs and rocks into their mouths," according to court documents filed during a lawsuit that resulted in a federal court order to close Hissom by 1994. "Eddie, a Hissom resident, was seen throwing up lying down on the floor and then eating the vomit."

That's the way Hissom was. Since 1989, the center has cleaned up its act, but problems remain.

Residents continue to be at risk of having personal belongings stolen, but abuse statistics are down.

There were 103 investigations of alleged abuse in fiscal year 1988. The number dropped to 77 in fiscal year 1990, according to reports from the Office of Client Advocacy, a DHS investigating arm.

Through May 1991, 11 months of the fiscal year, the agency received 51 referrals of alleged abuse or mistreatment. Investigators said 24 were not confirmed and 12 are pending. Six instances of abuse, eight of mistreatment and one of sexual abuse were confirmed.

Attorney Chase Gordon, Office of Client Advocacy director, said the sexual abuse incident did not involve rape.

"It was more of a fondling or a kissing. Sexual abuse was straining it, but it was what the committee decided on," Gordon said.

Better care at Hissom is due in part to more staff. Direct care staffing ratios have gone from one for eight clients to one for four since a federal judge ordered Hissom to begin placing clients into the community. That order also called for better care for clients in Hissom.

Consistent programming now helps keep clients busy 16 hours a day, Superintendent Deborah Rothe said.

"If the services that are available to the Hissom clients now had been provided the Hissom clients when this whole thing started, there never would have been a lawsuit," Rothe said.

Regardless of progress at Hissom, too much has gone on for it to make sense to fight now to keep it open, she said.

"It would always be that place that was so awful — that place the court had to close," Rothe said. "I don't believe because Hissom was once awful that all institutions are bad."

One problem hasn't abated.

"Theft is a major problem," Rothe said.

Hissom is an open campus with a small security force. Clients' clothing, TVs, VCRs and radios get stolen.

"We can't search purses or cars," Rothe said.

The state spends approximately \$5,000 a year to replace items stolen from clients, she said.

Thieves also take state property, most recently a computer, a computer screen and a typewriter. Tools also tend to walk off, Rothe said.

"If anyone leaves a radio on a desk, they're liable to lose a radio."

Rothe's locked living quarters recently were ransacked.

But good things are happening for the remaining 276 Hissom clients, including being served by the best psychologists in the state, Rothe said. She touts speech and occupational therapy departments.

All clients get physical therapy now, she said. When parents of six Hissom clients filed suit six years ago to have Hissom closed, only one full-time physical therapist was on staff to care for 600 clients, many with twisted bodies. That therapist had one aide.

Progress hasn't been without pain. Hissom employees and higher-paid technical consultants ordered in by the court have squared off in power struggles.

Problems arise when people who have been running programs for a long time suddenly are being told that everything they've done is wrong, Rothe said.

Phil Allen, a pharmacist at Hissom who heads the Employment Concerns Committee, said there was a purchasing freeze at Hissom at the same time experts were pouring in — experts making up to \$100 an hour, standing around criticizing a worker making less than \$5 an hour.

"The place started looking ratty. We couldn't afford \$7 to fix the tractor, but could spend \$7 million for somebody to tell us we needed to mow the place — typical of that era," said Allen.

Some staff training by outsiders paid off. Oklahoma lacked experts in the field of mental retardation.

"But we are very quick learners," Rothe said. "I think we can do now what we didn't know to do two years ago. I don't think we need the experts now that we needed back then."

The settlement to close Hissom was approved by U.S. District Judge James O. Ellison in January 1990.

"The consent decree has made things go easier because the lawyers aren't fighting anymore," Rothe said.

During a court battle, both sides will try almost anything to prove their point, she said.

As a result, innocent people get hurt. We can't relive the lawsuit. So, my concern is trying to patch up the hurt feelings."

Part of that hurt is that many of the staff members don't believe their story ever got told, according to Rothe and Allen.

Despite documented abuse and neglect at Hissom, dedicated Hissom employees who love and care for clients have always far outnumbered employees deemed guilty of abuse, Rothe said.

"There were 900 other workers who cared about them," Allen said. "We took them home with us. They went to church with us. Our children brought them Christmas and birthday presents."

Some clients had been at Hissom 20 years. Employees were the only family or friends some clients had, Allen said.

"We felt like parents who did the best we could with the resources we had — like those who, because of false information, had their children taken away and put in a foster home. We literally fear for the lives of these special people."

Employee resentment — heightened by fear about jobs and fear for clients being moved into the community — also helped send morale to an all-time low.

For a while, accusations against Hissom workers made it hard for them to get a check cashed in the community, Allen said.

At least now, no employee is expected to work a double shift back-to-back, Rothe said. Earlier, some employees had been required to work 32 hours out of 40 if someone didn't show up for work — two 16-hour shifts with eight hours off in between. Absenteeism is still a problem. The turnover rate of new employees — 30 days.

Longtime employees said at one time they might miss a few days of work and return to find the whole program changed — new forms, new procedures. The threat of adverse personnel action was great, Allen said.

He once likened it to being "like the devil threatening to throw us out of hell."

Employee conditions have improved. Allen credits Rothe with addressing employee concerns, helping raise morale.

Employee abuse of clients most often has happened when employees were exhausted, Rothe said. Residents at times have tried employees' stamina to the utmost.

"It's real hard to have an adult body and a child's mind. Sometimes, when staff is pressured and the kids keep doing the same thing over and over and over, they (employees) just lose it.

"We try to test that — try to train, try to do everything, but, I don't know how. All of a sudden, somebody just backhands a client, hits them with a belt if they won't do like they're supposed to."

Then, there are just some mean people, Rothe said. Those get weeded out, but sometimes after a client has been hurt.

► THE HISSOM CLASS

The Hissom class consists of all people who at the time of the filing of the complaint, May 2, 1985, and all people who became clients of Hissom during the pendency of the action; people with mental retardation residing in home who have been clients of Hissom within the past five years and who may be returned to Hissom; and people who have been transferred to skilled nursing facilities or intermediate care facilities, yet remain the state Department of Human Services' responsibility.

Empty homes' rent, blind eye to excesses run up bills

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

In its haste to satisfy a federal court order to close Hissom Memorial Center, the state of Oklahoma allowed excessive spending to go unchallenged for four years.

Instead of trying to contain excessive costs, the state ignored them. The needs of clients and the need to satisfy the court order came first and foremost. Costs were never discussed, only needs.

The result:

- The state paid rent on empty apartments and houses for a year and longer before Hissom clients were moved into them.

- ? "Phenomenal" overstaffing: as many as 11 aides per client, costing \$3,520 a week per client.

- ? Chaos in providing services, which often delayed implementation of plans, further increasing the costs.

- ? Clients were isolated in homes and apartments instead of being placed in groups of two and three.

- ? One client was left in a hospital from mid-1989 to May 1991, costing taxpayers hundreds of thousands of dollars, while the state tried to resolve placement problems.

- ? The best buy for the buck, foster care, was discouraged.

With its back against the wall in 1987, the state found itself unqualified to handle the task of establishing a comprehensive service system to care for the Hissom clients in communities: So the state began hiring experts and companies from around the nation to get the job done and to train Oklahomans. The name of the game was to get the clients out of Hissom — no matter what.

"We have now gotten to a point where we all agree to anything to spring someone from Hissom," a staff member told the Homeward Bound Review Panel.

The panel reported to U.S. District Judge James O. Ellison after visiting 80 clients in the community. It is comprised of three out-of-state mental retardation experts now responsible for monitoring the state's compliance with the Hissom court order.

Ellison presided over the Homeward Bound vs. Hissom lawsuit, which resulted in the 1987 court order to close Hissom and integrate its clients into community living arrangements.

As of June 1, 276 Hissom clients remain in the institution as the state struggles to train staff and provide for the clients so they can be placed in the least restrictive environments possible. They must be placed by October 1994.

At the end of June 1987, there were 441 people in Hissom. Some have died, some have moved out of state. By June 1991, 125 had been moved into the community.

Only recently has the state

costs, said Benjamin Damps Jr., DHS director since February. No one kept track of amounts paid to rent empty units, according to Eranell McIntosh Wil-

begun a concerted effort to contain rector of the DHS's Developmental Disabilities Services Division (DDSD). She quit May 15 amid legislators' criticism.



The last written report from the DHS Area II office in Tulsa, dated April 2, 1990, showed 48 percent of dwellings rented by DHS in connection with supported living contracts were vacant. DHS was paying rent on 37 houses — 17 vacant — and 34 apartments — 17 vacant.

Now, rents are never paid for more than two or three months before a client moves in, said Kathy Kovach, DDSD program administrator for Area II.

Many in the Hissom class live alone in supported living programs — some in three-bedroom homes with new furniture — smothered by habilitation training specialists and other service providers. Some dwellings appear almost stark while others are beautifully deco-

"There appears to be a prejudice against encouraging clients to have a roommate, and we wonder about the rationale for this."

— Homeward Bound
Review Panel

rated, the panel stated.

"We wonder if the state desires and is prepared to have vast numbers of individual placements with staffing around the clock," the panel stated.

Abundance of staffing seen by panel members was "a phenomenon ... never seen so many situations where there was such an abundance of direct care staff."

What such staffing levels give in security, they take away from the client in "independence, spontaneity and opportunities for learning in the normal environment," the report stated.

One-to-one staff, around the clock, seems to be the standard for clients, almost regardless of how high functioning or capable they are, the panel said.

"This business of the shift staff is terrible. It's extremely expensive and it's not really the best way to provide for the clients," said

Louis Bullock, plaintiffs' attorney in the Homeward Bound vs. Hissom suit. Other excesses the panel noted:

- Two full-time job coaches for one client.



■ Eleven

full-time equivalent direct care staff positions assigned to one client. DHS pays for-profit providers \$8 an hour for each habilitation aide (direct care staff), and \$23 an hour for job coaches.

While the panel suggests modern technology and one-time expenditures for equipment to solve staffing problems for people needing lifting, Wilson defended large staffs.

"In order to do seven days a week, 24 hours a day, you need 7.5 people to do it in the first place — just to have one," he said. "If the person at any time needs an extra person, 11 would not be totally out of the question. It would allow them to have two people when they need it (like for lifting)."

The weekly tab for 11 aides working 40 hours each would be \$3,520 — or \$183,040 a year.

■ Physical, speech and occupational therapy were noted for some individuals when there was no need or where they might be better served with power wheel chairs, electronic communication devices and other equipment.

■ "There appears to be a prejudice against encouraging clients to have a roommate, and we wonder about the rationale for this."

Advantages to two people sharing a home, like mutual support and interdependence, were listed.

Nobody's owning the decision to place so many clients alone without roommates, said Pat Wear II, executive director of the panel.

And no one wants to take credit for the state paying rents on properties vacant for up to a year.

David Powell, assigned by Ellison to oversee DHS compliance with the court order, had to sign off on all placement plans for approximately two years.

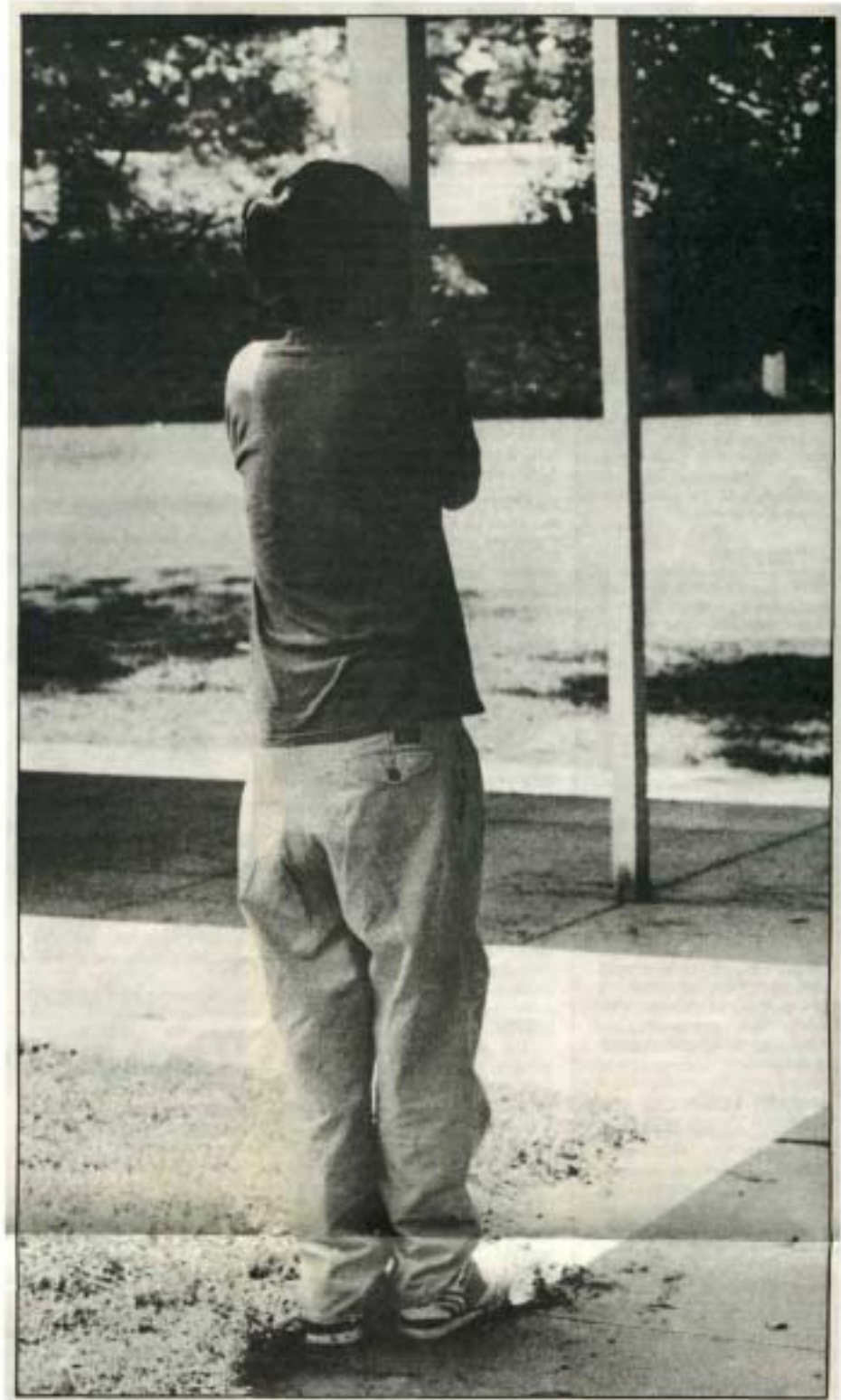
The plans were to have every possible contingency built in, Wilson said. It was a stringent process with little latitude for administration to say, "this makes no sense."

She said the panel "looks at it a little differently" and teams that decide on placement plans for clients now have more experience in coming up with a passable plan.

"It took time to get it down," she said.

Did she agree with many of the rank and file in DDSD who said Powell was too nit picky?

"He was just tough," Wilson said.



HISSOM MEMORIAL CENTER clients wander around the campus routinely.

Staff photo by Kristi Fry

► THE HISSOM CLASS

Hissom class members as of May 1991:

- 10 — Enid State School.
- 8 — Pauls Valley State School.
- 2 — non-specialized foster care.
- 16 — specialized foster care.
- 49 — group homes.
- 276 — Hissom Memorial Center.
- 51 — general nursing homes
- 29 — independently with minor supervision.
- 3 — incarcerated.
- 1 — mental health facility.
- 268 — private ICF/MRs.
- 49 — out-of-state situations. If they move back, they will retain client status.
- 15 — living with parents.
- 96 — living in the homes of relatives, not parents.
- 5 — supported, semi-independent living with a low per diem of \$19 a day.
- 174 — supported living.
- 8 — not located.
- 17 — dead (1989 through May 1991).

Powell said there were times he was picky because he promised no one would move before appropriate supports for them were established in the community. "If the staff wasn't trained the way they needed to be trained or the key conditions in place."

Placements were seldom delayed more than six months, "and I have no apologies," he said.

Clients couldn't leave Hissom without Powell's approval, and once they left Hissom, they weren't to go back. Take the case of Joe Savage, 21, who stayed in Tulsa hospitals for almost two years before being placed into the community in May 1991.

Records show Savage's hospital bills total \$190,000 since his 21st birthday in June 1990. Medicaid records showing hospitalization costs before he turned 21 are con-

fidential and can't be released, DHS told the Phoenix.

A March 1991 bill to Hissom Memorial Center from two Tulsa physicians requests Hissom pay \$16,800 in physician fees not paid by DHS or Medicaid while Savage was hospitalized.

Other excesses occur, like in staffing, because everyone in the team meetings is advocating for the client, said Jim Nicholson, interim director of DDS.

"Nobody is watching the purse strings in the team meeting," he said.

Sometimes, costs have been driven up under the premise of better to be safe than sorry, "and so the team apparently goes ahead and overprescribes," he said.

Bill Sagona, guardian ad litem for 245 of the Hissom class, said that in team meetings he's attended, costs are never discussed — only needs.

Staff number always has been a team decision, Wilson said. Teams tend to be more protective instead of less protective. Therapists, psychologists, the family, the client, Hissom staff, the community provider chosen for the client — all are part of the team. Plain tiffs' attorneys have input.

Cost containment is necessary and people have to question staffing levels. It has to happen, Nicholson said.

DHS Director Demps has formed a cost-containment committee to address the issue and has asked the review panel for assistance.

"The situation requires that the department be more assertive in the way tax dollars are being spent," Nicholson said.

But there has to be flexibility. "You can't establish guidelines that end up hurting people."

Has too much been spent for what was accomplished?

"To try to equate what the cost has been in terms of people's lives — to improve the lot of another human being — how can you say that wasn't worth it?" Wilson said. "I'm not going to be put in a position of saying that money spent on improving the life of an individual is not worthwhile."

Will public or legislative reaction to excesses hurt the program

for the developmentally disabled in Oklahoma?

"I don't know about the public," Nicholson said. "I don't think it will be the intent of the legislators to hurt the program. There may be some strings attached to require greater oversight or stricter guidelines."



Powell

The delivery system itself has hurt some mentally retarded in the Hissom class. Not all clients have shared equally in goods or services being given to those in supportive living.

The system discourages (from financial and staff support points of view) home or foster placements, with supportive living arrangements receiving favored treatment, the panel reported.

"This is particularly ironic because the effect is to force, by default, clients into a supported living arrangement, which may not be nearly as desirable and is far more expensive," the report stated.

The panel stated one family said it was next to impossible to have an habilitation training specialist (aide) assigned to a client in foster care.

That's what foster care parents are being paid for, Wilson said, to take care of the clients.

Wilson said foster home parents of Hissom class clients are receiving as much as \$40 a day.

But the amount paid to the foster families — up to \$1,240 a month — is much less than DHS pays providers to supply only one hab aide for eight hours a day — \$64 a day or up to \$1,984 a month.

The panel notes foster care placements represent enormous savings — compared to Hissom costs, supported living costs and other available options.

The panel suggests increases for foster care in:

- Per diem amount.
- Availability of habilitation aides.
- Respite relief.

Abuse haunts system

By **DONNA HALES**
and **KRISTI FRY**
Phoenix Staff Writers

The state is placing people with mental retardation and the public at risk in efforts to meet an October 1994 federal court deadline to close Hissom Memorial Center.

Safeguards are missing, everyone agrees. They're missing a year after the Hissom settlement agreement required development of internal safeguards to assure services to meet emergency needs of Hissom clients living in the community by June 30, 1990.

A three-month investigation by the Muskogee Phoenix found that concerns include:

- Exploitation and abuse from caretakers.

- Private agency employees involved in confirmed abuse cases moving to similar jobs with un suspecting employers.

- ? Failure of the state to provide clients with background information on direct care providers from other states.

- Insufficient sex education.
- A lack of emergency services.
- Clients with serious behavioral problems being placed in the community before gaining sufficient control to assure safety of themselves and others.

- Gaps in communication and medical and technical services.

"Recent events have demonstrated the lack of emergency services, any significant safety net, or even elemental communications in emergency situations," U.S. District Judge James O. Ellison was told in a final report of former court monitor David Powell.

The Oklahoma Department of Human Services received 44 abuse allegations in 11 months of fiscal year 1991 from among 174 Hissom clients living in the community. Investigators confirmed abuse.

- Insufficient sex education.

- A lack of emergency services.

- Clients with serious behavioral problems being placed in the community before gaining sufficient control to assure safety of themselves and others.

- Gaps in communication and medical and technical services.

"Recent events have demonstrated the lack of emergency services, any significant safety net, or even elemental communications in emergency situations," U.S. District Judge James O. Ellison was told in a final report of former court monitor David Powell.

The Oklahoma Department of Human Services received 44 abuse allegations in 11 months of fiscal year 1991 from among 174 Hissom clients living in the community. Investigators confirmed abuse, neglect, mistreatment or exploitation in seven of those cases by the end of May. Sixteen investigations are pending.

An 8 percent increase in alleged abuse of people with mental retardation in the first half of the year is almost entirely attributable to allegations of abuse involving Hissom clients now living in the community. The information

was released in a report from the Office of Client Advocacy, an investigating arm of DHS.

DHS refused to release specifics about the abuse reports, even with the names of clients marked out, citing client confidentiality.

Abuse of clients in the community usually comes from those who (See SOME on Page 9)

Some fall through holes in safety net

(Continued from Page 6)

work with them, Powell said.

Abusing caregivers now can move from program to program, generally without detection, said Chase Gordon, administrator of the Office of Client Advocacy.

It's a common concern of staff responsible for Hissom clients in the community, Gordon said.

Background checks aren't always made before a person is hired, as in the case of the alleged rape of a 26-year-old former Hissom client by a member of her direct care staff.

DHS requires that provider firms not hire any person convicted of a misdemeanor or felony, excepting traffic violations, to provide services to handicapped people if the conviction directly relates to the person's ability to perform the job.

But background checks of direct care staff would not necessarily show prior improprieties with clients, Gordon said. Private agencies may be reluctant to report the reason for separation.

Bill Sagona, court-appointed guardian ad litem representing 245 Hissom clients, said the alleged assailant is no longer working with Hissom clients.

"In that one, there was a lack of a background check," Sagona said.

Insufficient sex education of clients living at Hissom is a drawback, Powell said.

Hissom Superintendent Deborah Rothe said adult Hissom clients had been taken to visit former Hissom adults of the opposite sex who now live in the community.

Rothe and Powell skirted the issue of whether the Hissom staff had been required to take residents for conjugal visits.

Adults have been together by themselves, Powell said.

"Let's just call it sex and re-

"Service provision seems to occur more as an obligation. Some home living providers treat an individual's home as the provider's home and the individual as a guest. "Adults with mental retardation are typically not treated as peers who happen to have additional needs for support."

— David Powell,
former court monitor

sponsibility ... that's an issue in life," Powell said. "There are an awful lot of parents in the world that I wish somebody had spent some time talking to about conjugal visits."

Hissom clients have rights of choice, Powell said.

The staff has responsibility to help them think through the issues involving sex and help them be prepared, he said.

"If I'm satisfied they are, it's OK with me."

DHS response to client crisis situations also gets rapped in a report from the Office of Client Advocacy.

"Adequate emergency resources haven't been developed," the report said, citing poor response times from a crisis intervention team and a shortage of emergency respite care for clients in behavioral crisis.

The report notes that shortages in community resources, professional staff, foster home providers, habilitation training specialists and respite care providers "seriously jeopardize some existing placements and appear to be impeding future planned transitions from Hissom."



Provider firms have been chosen purely on their ability to satisfy Oklahoma paper and interview requirements, the Homeward Bound Review Panel stated in its last formal report to Ellison.

"Performance levels and a provider's standing with past and present contractors should be researched by DHS before contracting," the panel stated. That information should be supplied to consumers.

Clients in the community also face gaps in services. If DHS doesn't have a service available to meet a client need, or is slow in obtaining it, the service often is simply not delivered and gaps exist, Powell said in his final report to the court.

The gaps have been reported regularly, he said.

Some needed services are left off client's habilitation plans if it's known the services aren't available, he reported.

The system in place for Hissom clients in the community doesn't significantly reflect clear valuing of people with mental retardation, Powell told the court.

"Service provision seems to occur more as an obligation," he said. "Some home living providers treat an individual's home as the provider's home and the individual as a guest."

"Adults with mental retardation are typically not treated as peers who happen to have additional needs for support. While class members usually attend their own team meetings, there is often no effort to involve them."

Powerless no longer



ALBERT BROWN, left, has a great sense of humor. Hissom Memorial Center resident, and Vandiver said his job coach, Jon Vandiver. Albert, a former have grown close working at Mohawk Park Zoo.

'Sticking pry bar into machinery' gets ball rolling

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

People with developmental disabilities and mental retardation and their families have been powerless in Oklahoma.

They've had no voice, no clout, no organized advocacy group to lobby legislators and community leaders, a three-month investigation by the Muskogee Phoenix shows.

That's why thousands of Oklahomans with disabilities receive little or no help, said Louis Bullock, attorney for the plaintiffs in the Homeward Bound vs. Hissom lawsuit, which establishes the framework for a community service system that will serve as an alternative to institutional care.

However, because of the lawsuit and new federal laws, the Americans with Disabilities Act and the Education for All Handicapped Children Act, the power of the powerless is emerging in Oklahoma.

"The way we get those folks services is by making clear what their need is and sticking the pry bar into the machinery and making it respond," Bullock said. "Ultimately — one of the things that hasn't been done in this state — we've got to organize a real state advocacy group for clients and their families."

Most Americans are unaware of how many people will benefit from recent federal legislation, according to the Center for Human Policy at Syracuse University. Most people do not see themselves as part of the community that receives benefits. However:

More than half of the families in the United States include a member with a disability who receives some kind of support from recently mandated federal legislation.

Other efforts under way in Oklahoma to find solutions to providing comprehensive, accessible and available family support services:

A special task force has been established by the Legislature to study the delivery system of aid to people with developmental disabilities and mental retardation. State Rep. Gary Maxey, D-Enid, is heading the 27-member task force.

"All of us realize we need to do

everything possible to avoid another Hissom and the absurd expenses created by the lawsuit which resolves that case," Maxey told a state newspaper. "Our task force is directed to create a comprehensive plan to deliver services. ... This type of long-term planning (See POWER on Page 11)

Power of the powerless emerging

(Continued from Page 6)

will help prevent Hissom-type situations."

■ The Oklahoma Department of Human Services has set up a cost-containment committee to address excessive costs in setting up the program of community placement. U.S. District Judge James O. Ellison has ordered that parties agree on a format to file all expenses connected with the Hissom case in the court record.

Ellison also issued an order May 17, 1991, informing the parties in the lawsuit that "in the future, no order will be signed which merely sets out dollar figures to be paid and fails to document the precise calculations which led to the requested money figure. The parties must, in connection with the order signed today, file with the clerk's office by May 28 detailed, supporting documentation setting forth all calculations."

■ DHS officials are traveling around the state this summer to find out how it is meeting, or not meeting, people's needs. They also are spreading the word about what the agency can and cannot do. It's a public policy approach to the problem that DHS hasn't had in the past, said Benjamin Demps Jr., the agency's new director.

That input, along with lessons learned from placing Hissom class members into the community, should provide a clearer vision of what Oklahoma wants its policy to be, Demps said. For instance, Demps isn't convinced that all people with developmental disabilities and mental retardation should be placed in supported living.

"When we start getting to those difficult cases, then there's going to be the true test of the theory that community living works for everyone," he said. "Some are going to make it. Some are going to grow. But as we get to the more difficult cases, who knows, we might have to say, 'Well, maybe this won't work for this person.'"

"The problem is, we as a society like to say, 'Well, it didn't work for this one, it won't work for the rest,' " Demps said. "We can't, because these are human beings and have a capacity."

■ Demps has asked two state universities to give him a proposal for establishment of a human services research institute.

"That institute would take all of the demographics in the state pertaining to human services we deliver, it would take the specialty areas of Developmental Disabilities Services and Aid to Families with Dependent Children and child abuse and pathology of social welfare and all that kind of stuff, and it would work it, look at it, model it, cost it out and look for other approaches from the state's point of view, not from the federal government's point of view."

At the same time, DHS would take its employees who don't have master's and doctorate degrees because they can't get them, and give them an opportunity to study as they become experts.

"Pretty soon, you would have a cadre of experts coming from the state. The state must produce its own. You can't keep hiring them from out of state," he said. "You would think that we would have an institution in Oklahoma that would issue a doctorate in human services administration. If we don't do that, we're always going to be trying to catch up with the rest of the nation."

■ The Homeward Bound Review Panel, which oversees the transition of Hissom clients into the community, recommends having a state medical director or outside medical specialist experienced in developmental disabilities perform an annual medical quality assurance review of Hissom until the facility closes. The specialist also would oversee appropriate medical services for people with developmental disabilities statewide.

There are sufficient medical issues at Hissom to warrant medical inquiry, which must be done by another physician, the panel said. Death reviews, unexplained fractures and a higher-than-expected rate of gastrostomy insertions should be examined.

■ A Care Council for Developmental Disabilities in each of the 77 counties is a new project by the Oklahoma Area Health Education Center Program, College of Osteopathic Medicine, Oklahoma State University. The mission: provide community awareness, resources and education on issues related to developmental disabilities.

Muskogee is one of the first four counties where a council will be established, said Debra S. Starnes, program administrator and coordinator of development.

"One of the main goals will be to inform the community, get people involved and promote the issues."

Other goals: increase community knowledge of the methods and philosophies behind community integration; increase the number of businesses willing to participate in supported employment projects; promote a positive community change in attitude toward persons with developmental disabilities; provide technical assistance and support to organizations.

But the real solution to better care for people with developmental disabilities and mental retardation is parent power — thousands of parents beating the drums across the plains of Oklahoma, two staunch advocates said.

Those who are not receiving state services and who resent what Hissom class members are receiving can do more for their cause than anyone can if they focus their efforts in the right direction, said attorney Bullock.

"One of the things that happens is that folks get to playing against



Staff photo by Kristi Fry

A YOUNG CLIENT at Hissom Memorial Center spends hours staring out a large plate-glass window. By October 1994, the youngster will be placed in a less restrictive environment in the community.

one another," he said. "You know, the folks who aren't getting services look at the people in the Homeward Bound and say, 'Well, I'm not getting services because you're getting too good a services.' That's a wonderful game to be played and if I was opposed to community services, I would encourage everyone to play that game because that assures political paralysis of the families.

"They fight over the same piece of pie," Bullock said. "The way that we have to do it is we've got to make the pie larger."

Pat Wear II agrees. He is executive director of the Homeward Bound Review Panel, established by the court to help administer the program to move Hissom class clients into the community.

The course should be "to fight for equal resources for those folks who are not class members," he said. Oklahoma does not have a state-wide chapter of the National Association for Retarded Citizens. It needs one, Wear said.

"Parents and individuals with disabilities and other interested people have got to put differences aside and organize themselves as an effective citizen advocacy agency."

Programs are funded better in other states "because they are able to bring effective pressure against the government to do the right thing," Wear said. Oklahoma desperately needs "somebody that can coalesce the factions in this state and bring them together as a political power.

"It's just not here, and it hurts," Wear said. "... And nobody does it better than a parent. Nobody does it better than a parent because they can look a legislator in the eye and say, 'Don't BS me, I got a kid and I got needs here. You going to meet them or not?' "

"When we start getting to those difficult cases, then there's going to be the true test of the theory that community living works for everyone. Some are going to make it. Some are going to grow. But as we get to the more difficult cases, who knows, we might have to say, 'Well, maybe this won't work for this person.'

— Benjamin Demps Jr

'Locked up' for years, Albert's free

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

TULSA — Albert Brown is free at last.

Free to work, to fish, to go out on a date. Free to live where he wants. Free to choose his own friends, to do normal things that all Americans have a constitutional right to do.

Albert's proud of that.

He paid dearly for his freedom — 11 years in a state institution for people with mental retardation. He always knew he could handle it, but no one would listen.

"You always stayed locked up. You didn't go very many places," said Albert, 24. His needs were met "sometimes" and he was abused, he said.

"If they didn't get their way they'd take a scrub brush and hit you with it. ... I'd tell them, 'I'd like to get out of there someday.'"

hey'd say — 'someday.'"

Someday finally came for Albert when a federal judge ordered Hissom Memorial Center in Sand Springs closed by 1994 and its clients moved into the community to lead fuller, more productive lives in less restrictive environments. As a Hissom class member, Albert is receiving a full array of state services in his supported living arrangement. He lives with two other Hissom class members, friends he'd made at the institution.

Albert was committed to Hissom at age 9. He's a person with moderate to mild retardation, but his job coach said most people who work with Albert don't have any idea.

Albert lived in a group home for people with developmental disabilities after leaving Hissom four years ago. He "kind of liked it and kind of didn't" like it. He met the

woman he wants to marry at Hissom. She lived at the group home, too, but:

"I wanted to go more places instead of having people transport me," he said. "I didn't like telling people where I was going. I couldn't stay home by myself or anything."

Several months ago, Albert moved into a house with his roommates. The Oklahoma Department of Human Services provides a house manager for the three. She works 40 hours a week programming — showing the men how to shop, manage their time and money, write checks and balance a checkbook.

The three also have someone there to supervise them for 32 hours on weekends.

"We're here to get them where they need to get the best way they can," said house manager Molly

(See ALBERT on Page 11)

Albert's free at last

(Continued from Page 6)

Keener. They make mistakes, but they learn from those mistakes.

Albert's first job was at Page Belcher Golf Course as an assistant mechanic.

The only reason he got the job was because he told his future boss, "I want this job," said Jon Vandiver, his job coach.

"Because he knew what he wanted to do, that's why he was allowed to try, and he proved himself," Vandiver said.

Now, Albert works at Mohawk Park Zoo.

Albert also helps his landlord mow lawns. His earnings have enabled him to be more self-sufficient. He's no longer a recipient of a federal Supplemental Security Income check.

Albert gets up on his own and gets to work by 7 a.m. He calls a taxi or networks with friends. His DHS case manager, Libby McCarter, says she's seen him reach a potential he always knew he had.

Albert was placed in Hissom because there were neither community services nor special education classes to meet his needs, McCarter said.

"Who knows who would not be labeled like that if they had been exposed to the same opportunities as Albert had as a child," McCarter said.

Albert lived in a foster home in Stilwell

before going to Hissom.

"He's a taxpayer. He earns his keep," Keener said. "He's just happy and proud. He knew all along he could do this. He just needed the chance."

Albert took a home economics class at Hissom. When he's hungry, he cooks or goes out for a hamburger. He enjoys simple things most people take for granted; being able to call a friend on the telephone or just walk to the store. Of course, he'd rather drive, but he can't afford a car — yet.

He likes going over to a sheltered workshop where his girlfriend works on his days off. If there's a lot of work to do, he volunteers to help.

He's saved \$1,200 toward his main goal of purchasing a car, putting his first check into the credit union. He's successfully completed a driver's education course and has a driver's license.

The first purchases he made with money he'd earned: "I bought me a waterbed. I bought me a bird. I bought my girlfriend some rings."

Albert earns \$6.27 an hour. After his six-month probation is up in August, his wage could go up to \$7.04 an hour. Benefits include health and dental insurance, access to a credit union, retirement and a vacation.

Vandiver trained Albert at the zoo. He's still working with Albert but is fading out because of Albert's progress.

"He's a good, hard worker," Vandiver said. "When Albert makes mistakes, he doesn't make excuses. He just goes and fixes them. Every obstacle he's presented, he's overcome."

Albert supervises community service workers ordered by the court to work off fines for driving under the influence and other offenses, in addition to performing maintenance duties. A lot of people didn't think he could handle the supervisory part, Vandiver said.

"He doesn't back down from anything. He just goes after it and does the best he can. I'd like to have a hundred clients like him."

Albert's happy. He wants to be happier. His goals: buying the car, of course; living on his own; marrying the girl from Hissom, the girl who became a part of his hopes and dreams long ago in a place where Albert wasn't free to pursue those hopes and dreams.

Those goals are attainable now, though, McCarter said.

"Albert has a lot of natural support systems. He's such a nice person. He goes to church . . . has a lot of friends he visits and who visit him."

Albert Brown is free at last.



Earl's newfound rights 'about to destroy him'



EARL HEGINBOTHAM isn't a bad pool player. He loves eight ball and nine ball. He frequents Muskogee bars, plays pool and drinks beer.

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

Earl Heginbotham, 34, has the mental capacity of a 10-year-old, but he can hold his own in a game of eight ball against all takers at some of Muskogee's seediest bars.

He loves a cold beer, chain smokes when he has cigarettes, and likes to gamble.

For Earl, who's spent most of his 34 years in state institutions, group homes or nursing homes, life is looking up. The state pays for his apartment, which he shares with another man, provides round-the-clock supervision, a job, money for food, clothes and spending cash.

Earl's new lifestyle is the result of a federal court order to close Hissom Memorial Center in Sand Springs by 1994. The court ordered that present and former residents of Hissom are entitled to the same rights and freedoms all other Oklahomans exercise. But along with freedom comes responsibility, and that's where people like Earl are at a disadvantage.

Bea and Ray Heginbotham placed Earl in Hissom when he was 10, three weeks before his younger sister was born in 1967. He left Hissom for the first time in 1975. His last release from a state institution for people with developmental disabilities was in 1984. He has been placed in supported living in 10 different towns.

"He's been all over the state," Bea Heginbotham said.

While his parents have remained Earl's guardians, they have little control over what he does in supported living. There have been numerous problems. For instance: *f* While Earl was living in Wagoner, his furniture the state purchased disappeared.

"He said he gave it away," said Bea Heginbotham. Others contend Earl sold the furniture for cigarette money. "He was so proud of it, I couldn't believe he got rid of it."

f A woman from a group home in Jay drove Earl to his parents' home in Catoosa and "just set his clothes out in the driveway and let him out of the car," his mother said. "She said, 'We've had it — he's out.'"

f Earl lived in an apartment in Claremore. That didn't work out.

"There's things they let him do I don't think is right. I'd be happier if they didn't let him go to the bar."

— Bea Heginbotham,
client's mother

local bars in Muskogee. He drinks beer, plays pool and often causes problems.

"There's things they let him do I don't think is right," Bea Heginbotham said. "I'd be happier if they didn't let him go to the bar."

So would Louise Bennett of Muskogee, a staunch advocate for people with developmental disabilities who has been a friend of Earl's for nearly two years. The supported living program established for Hissom class clients hasn't been a blessing for Earl, she said.

"The program has destroyed all his self-esteem," Bennett said. "He knows how to get all the freebies."

Earl does his own laundry and keeps his apartment neat and clean. He likes the apartment better than the group home he came from.

"You have more freedom in a place like this," he said. He can't handle money. It is doled out to him in small amounts or "I'd blow it all."

Cigarettes also are meted out to him. If he got the whole carton at one time "he'd smoke them all," said one of his habilitation aides, Viola Cypert. She takes him fishing, to play bingo and to the bar when that's what he wants. She lets him off at the bar, then returns to his apartment until he calls or walks in the door.

Earl denies having an alcohol problem.

"I just go in there for the fun," he said. "If somebody buys me a beer or two beers, it almost blinds me. But if I get up there not a drinking, I can beat almost anybody at pool."

Earl says he's been physically beaten at the bars.

"When a woman hits me, it doesn't hurt," he said. "The other night I had a big man chasing me. I hadn't done anything — he was just drunk."

Earl hasn't learned "that there

'His rights are about to destroy him'

► A NIGHT AT THE BAR



Staff photo by Kristi Fry

A BEHIND-THE-BACK shot is no problem for Earl Heginbotham.

With \$6 to spend, Earl takes his cue

By **KRISTI FRY** and **DONNA HALES**
Phoenix Staff Writers

Earl waltzes into Suzie's Bar as if he owns it, goes to the pool cue rack and starts eyeballing and shaking cues. But before Earl can put his money down to play, the bartender promptly tells him to leave.

"You put that down and get out of here," Judy Kuykendall exclaims. "You can't come in here. Get out!"

"I'm going to play pool," Earl responds.

"No you're not. I want you out," Kuykendall insists.

Earl places the pool cue back in the rack and quickly walks out of the bar.

"I'll just go across the street," he says.

"Fine. Go," Kuykendall says.

The lights are dim at American Bar, Broadway and Cherokee Street. Several people sit on tattered stools lining the bar. In the back at a lone pool table, a lamp hanging overhead spotlights the green felt where two men trade shots in a game of eight ball.

"I'm going to play," he announces.

"Fine, but you'll have to wait until we are through, Bud," says one of the men, irritated by Earl's pushy approach.

Earl backs away and sits down at a nearby booth. A moment later he jumps up and goes to the bar for a draw of beer. He takes a drink as he sits back down.

"Ahh, that's cold. Just the way I like it. I like it real cold."

Before the two men at the table finish their game, Earl sucks down two beers. He heads back to the bar for a third before starting his first game of pool with the winner of the eight-ball game. Earl asks about playing for money.

"No," the man says. "I never gamble."

"OK. ... No problem," Earl says. Then the man offers to play for a beer. Earl says OK, and racks the balls on the table.

Earl wins the next three games. He guzzles down three more beers. He then loses his fourth game of the evening to the man he beat in the first game. Although they hadn't wagered a beer, Earl treats the man to a bottle of Bud.

In less than one hour, Earl plays four games of pool and drinks six beers. Earl is soft-spoken and polite. But as the beer begins to intoxicate him, he becomes louder and less inhibited.

Earl once won \$100 in a pool game. But the man he won it from got him drunk and won it back, Earl said.

Earl spends three and one-half hours at the bar, then leaves after his \$6 is gone. A small man in stature, Earl usually causes problems at the bars he frequents, according to Kuykendall.

"He doesn't pay for his beer. Sometimes, he bets a pitcher of beer and when he loses he runs out the door," Kuykendall says. "The guys he makes mad at him are a lot bigger. One time, three or four guys chased him around outside on the street. If they had caught him they would've hurt him."

Earl got caught July 1 at the 108 Bar, just around the corner from American Bar.

Earl and another man argued and ended up fighting, said owner Beverly Liles, 44, of Muskogee. Earl was hit in the wrist with an ashtray. It knocked him into a booth, Liles said.

Muskogee Regional Medical Center confirmed Earl was treated for a fractured bone in his hand July 2 and released.

Liles doesn't believe Earl is mentally incompetent. She said she had spent hours talking to Earl about his problems.

"He's got an attitude that he wants to die and he wants someone else to do it," Liles said. "He can't commit suicide. ... He's got some deep embedded problems."

Earl has created disturbances at 108 Bar in the past, too, Liles said. She has tossed him out three or four times.

"This kid has got something way down deep in his past that he won't let go of. He's not mentally incompetent," she said. "He's got a real serious problem with life — and it's not craziness."

Reshape body or wheelchair?

State pours
\$6.5 million
into idea with
few backers

By DONNA HALES and
KRISTI FRY
Phoenix Staff Writers

A Florida firm hired to provide wheelchairs for clients at Hissom Memorial Center is using antiquated methods that result in posturing "analogous to a torture rack."

That's the opinion of Adrienne Falk Bergen, a former instructor in Columbia University's physical therapy program, trained neurodevelopmental therapist and noted author and lecturer.

The controversial philosophy of Progressive Therapeutic Services' owner and president, Lee Phillips: Deformed and twisted bodies can be altered by the use of a properly designed wheelchair.

Phillips believes in the method, but can't prove it scientifically, she said.

She hasn't had to. A federal judge ordered the state to hire PTT in 1986 to provide physical therapy and seating fabrication. The firm has been paid more than \$6.5 million in less than five years. PTT also provides physical therapy services at Hissom.

Trying to alter a deformity with a wheelchair would be more apt to stretch a client against a deforming force, because of gravity, Bergen said. She is not alone in criticism of Phillips' philosophy.

"Few feel as we do," Phillips said. "A lot of therapists would highly question whether you could make changes with these people — especially up into the teen years. But by experience, we've seen the changes come."

Other detractors: an expert in orthopedics, a Tulsa engineer and designer of wheelchairs, a physical therapist, parents and the Homeward Bound Review Panel, three experts who monitor placement of Hissom clients for the court.



Staff photo by Kristi Fry

"EVERYBODY IS STUCK like this," physical therapist Maria Toney says of Hissom Memorial Center clients in Sand Springs who are fit in wheelchairs designed to reverse deformities. "Their chairs look good, but they don't serve the purpose — everybody's fixed."

"So far as I am aware, there is no scientific evidence that would indicate that any type of seating device can do anything other than accommodate a patient," Dr. J. Andy Sullivan of the University of Oklahoma Health Sciences Center wrote to a DHS official in April 1991.

PTT's philosophy can lead to "gestapo" seating and is antiquated, said Charles Laenger, a Tulsa engineer who helps design wheelchairs. Laenger made the statement several years ago when PTT began servicing Hissom clients. Since publicly criticizing Phillips in 1989, Laenger has declined comment.

Maria Toney, physical therapist at Pauls Valley State School for people with mental retardation,

says comfort guides her philosophy.

"To me, you can't be functional if you can't be comfortable," Toney said.

Foam molded around the body of a developmentally disabled client is the basis for a wheelchair seating insert at Pauls Valley. Inserts are covered with terry cloth and then siliconed for better wear.

Pauls Valley clients with deformities receive pressure relief cushions filled with gel. Electronic wheelchairs are adapted so people can operate them with either the help of a laser on a head band or with their chin.

Robert and Judith Robison of Tulsa had to petition the court for permission to hire another firm to replace their son's wheelchair.

The Robisons told the court that a \$5,700 wheelchair designed by PTT for their son, Brian, was instrumental in his becoming bed-fast. Brian had outgrown his old wheelchair before PTT arrived at Hissom. He waited until August 1988 to get his chair and tried to tolerate it through late spring 1989.

Brian was unable to do so because the wheelchair caused acute pressure areas and skin breakdown, his parents told the court.

Judith Robison, a registered nurse, was concerned that no order from an orthopedic specialist was obtained before PTT designed the wheelchair.

Her letter to the court stated a habilitation team, which was to decide on her son's wheelchair needs, was overruled by Phillips and discussions got so heated that Hissom staff members walked out of the session.

"Until this cancer, PTT, is removed from the scene, the current situation at Hissom will remain unchanged," the Robisons wrote U.S. District Judge James O. Ellison in 1989.

Brian merely needed to build up a tolerance for his PTT wheelchair, Phillips said.

PTT's process does not necessarily lead to a comfortable chair, said David Powell, former

court monitor in the Hissom suit.

"Overall, I think they (PTT) do the best job of anyone I've ever seen," he said. "In individual instances, they have not delivered rapidly."

The Homeward Bound Review Panel issued a report to the court in 1990. It said panel members noticed "heavy stainless steel wheelchairs where electronic communication aids and ultralight chairs would be far more preferable."

The panel then consisted of two out-of-state mental retardation experts. A third member who since has joined the panel, Karen Green-McGowan, agrees with PTT's philosophy, said Pat Wear II, the panel's executive director.

Phillips told the Phoenix that her seating philosophy has little support nationwide.

Wheelchairs might help prevent future deformities, Bergen said. But equipment used while reclining on one's side, outside of seating, is best to help promote change, she said. Many times, severely impaired people have to try that type of alternate positioning before major seating is designed. Surgery is sometimes needed first, or anti-spastic medication used for a time, Bergen said.

No one person should decide on a wheelchair for anybody or everybody, Bergen said.

"Nobody's decision is right all the time," she said.

A team should decide what wheelchair to use, Bergen said.

Phillips said a team does decide what a person's equipment needs are and PTT then tries to design a chair to meet those needs.

Part of the struggle with PTT has been giving a product based on a team decision and having problems because teams formed slowly at Hissom, Powell said.

PTT continues to have that problem. A Phoenix reporter observing a team in action in June noted PTT therapists waited 50 minutes for several Hissom employees to trickle in. Of those who came late, two were substitute team members who said they knew little about the needs of the client being evaluated.

Physical therapists will continue to argue over whether a wheelchair can essentially allow an individual to possibly regain skills or whether the role of a physical therapist is to contain and prevent further deformity, Powell said.

"I heard both sides and I saw both sides, but never really came to any conclusion. I conceded the fact I'm not a PT and because of the situation, I wasn't opposed to them exercising some choice. I wanted them to exercise it carefully."

He's not too surprised by the disagreements over philosophy.

"Any doctor — no matter how good doesn't have the time and energy and attention — the best doctor in the world doesn't — to know everything they need to know to serve this population," Powell said.

Fraternity of experts finds work in closure

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

Incestuous connections permeate the relationships between consulting companies and out-of-state experts involved in closing Hissom Memorial Center at Sand Springs.

Some companies and experts, who came to Oklahoma as a result of a federal court order, have direct links with each other from Alabama and Arizona, to Minnesota and Michigan, to Florida and Nebraska.

Witnesses who were paid during the Hissom case, filed in 1985, to testify about the need for certain programs for Hissom clients later were hired to initiate and oversee these programs.

David Powell is a prime example. He was an expert witness for the plaintiffs vs. the state of Oklahoma. His wife, Lin Rucker, was, too.

Later, Powell was appointed court monitor by U.S. District Judge James O. Ellison. Powell was to be the court's "eyes and ears" in seeing that the Oklahoma Department of Human Services complied with the court order.

Powell had dealings with a medical and technical consulting company, Therapeutic Concepts Inc. (TCI), before and after he was appointed court monitor in Oklahoma. He said he worked as a subcontractor with TCI in Florida once for two days. Court records show he worked as a TCI consultant in connection with the Hissom case before being appointed monitor, a fact he denied once in an interview with the Phoenix.

He recruited two TCI transfers to Oklahoma, Holly Morrison and Brian Waddel, so they could develop firms to provide employment and support services to model plan clients.

TCI has billed the state of Oklahoma \$4.9 million for services.

Powell said he sees no conflict of interest in the matter.

Eileen Cox, a New England native and former partner in Progressive Therapeutic Technologies (PTT), testified on the inadequacy of physical therapy at Hissom.

PTT is a company, formerly of Florida, that designs and makes wheelchairs and adaptive equipment.

The company is now in charge of physical therapy at Hissom and makes equipment for the institution's clients.

PTT President Lee Phillips said Cox dissolved her partnership in PTT and moved back to New England in mid-1989. She said Cox still works for PTT "maybe six weeks a year." PTT billings to DHS show Cox receives payment under the category of "continuing education." For May, July and September 1990, she was paid \$10,599.78.

Though not all experts testified in the Hissom lawsuit, there are other connections:

■ Dan Broughton, a longtime Oklahoma DHS programs administrator, serves as a liaison between DHS and other lawsuit parties, including Powell.

Powell, now residing in Phoenix, Ariz., is no longer court monitor in Oklahoma, but remains administrator of the model plan he set up to serve seven Hissom clients. He also consults in New Mexico, Iowa and Great Britain.

Broughton and Powell consult on the same side of a Wyoming agreement to close institutions there. Neither Powell nor Broughton view working on the same side of the issue in Wyoming and occasionally working on opposite sides of a similar issue in Oklahoma as a conflict of interest.

■ Bill and Janet Sagona came to Oklahoma from Florida as TCI consultants in 1987. Janet Sagona still works for TCI.

The court appointed Bill Sagona guardian ad litem, effective Feb. 1, 1989. That means he is the advocate for Hissom clients who are wards of the state or whose parents don't take an active interest in their care.

■ Eranell McIntosh Wilson was hired in 1988 by DHS as administrator of the Developmental Disabilities Services Division (DDSD). She had been instrumental in closing institutions in Michigan and Alabama.

Wilson imported former employees and associates with whom she had worked in Michigan and Alabama for newly created posi-

"The Hissom staff believed the experts would pass on through like ticks, mosquitoes or flies or pollen when it frosts. But they didn't leave. They brought in more ... another group that just happens to be related to, or acquainted with, all the others. We joked that this was more evidence that cousins shouldn't marry."

- Phillip J. Allen, a pharmacist at Hissom Memorial Center, distributed the above to fellow workers. Many were upset, as he was, with "out-of-state experts" who all seemed to be tied together in a massive conspiracy against them.

tions as medical consultants at Hissom. She recruited others for DDSD administrative slots.

Hissom administration costs have almost doubled in less than five years — from \$1.2 million in 1987 to \$2.1 million for nine months of fiscal year 1991, according to a summary of Hissom court-related expenditures obtained by the Phoenix.

The per diem cost of client care at Hissom went from \$129.39 from July 1987 to \$276.86 by June 30, 1990. Data for fiscal year 1991 is not available.

DHS Deputy Director George Miller said at least four Wilson recruits received temporary salary increases to pay state-arranged loans for moving expenses. DHS records show the pay boosts were for 12 months and the highest was for \$510 a month.

Wilson said she had been acquainted with Paula R. McCaghren and her husband in Alabama. The McCaghrens created a firm to develop a pool of habilitation training specialists who would provide direct care for Hissom clients in the community.

The firm, McCaghren and Associates Inc., received a \$383,000 start-up contract from DHS.

A DHS audit, dated March 25, 1991, indicates the contract was unusual in that its funding was



"front-loaded."

That means a disproportionate percentage of funding was provided during the first half of the contract, rather than the second half, Tom Walls, a Senate fiscal analyst, re-

ported to legislators. The financing mechanism was not made available to other vendors providing identical services for Hissom class members.

Wilson said McCaghren and Associates was awarded a contract on the merit of its written proposal.

"Are we saying we don't want out-of-state companies to come into Oklahoma to establish an economic base to hire Oklahomans to work?" Wilson said. "Should people be given contracts because of where they live or who they are, or because they are going to give good services?"

The audit also reports that McCaghren and Associates fell \$50,918 in arrears on federal withholding tax; spent 43 percent of its total income in fiscal year 1990 on administrative salaries and taxes; and spent nearly \$3,900 from its start-up contract to assist administrative employees in moving from Alabama.

The firm remains under contract with DHS.

Wilson resigned in May 1991. DHS records show the people she brought in remain on the job.

Model plan spares no expense



Staff photo by Kristi Fry

DEVELOPMENTALLY disabled Jarrett Crossland, 10, of Muskogee rests on the living room floor of his home.

1 client's yearly cost: \$234,000

By **DONNA HALES**
and **KRISTI FRY**
Phoenix Staff Writers

Robin Bullock can't walk. She can't speak. She has trouble controlling her muscles. Three years ago, at age 29, she weighed less than 75 pounds. She was withdrawn and dependent on others for all her needs.

Now, she has favored status among people with mental and physical disabilities in Oklahoma. She is one of six clients from Hissom Memorial Center in Sand Springs who live in the community and participate in a model plan.

Robin has the best of everything — round-the-clock care, superior equipment, expert staffing, therapists, even a customized van.

She works five mornings a week at a Broken Arrow learning center. She runs a slide projector, using a custom switch to advance frames at the sound of a tone.

The model plan was authorized under a federal court order to close Hissom by 1994. The purpose was to place institutionalized people, like Robin, into society's mainstream and show a state, sadly lacking in mental retardation expertise, what could be — and what should be.

The problem: It costs \$234,000 a year to care for Robin alone.

Hissom expenses, particularly those of the model plan since its inception two years ago, have staggered state mental health insiders. To date, taxpayers have paid more than \$2 million to serve seven clients, a minute fraction of the state's 90,000 physically and mentally disabled residents.

Intentions were good. After the first year, average expenses for model plan participants were supposed to cost no more than if the clients had remained at Hissom — \$175 a day, or \$63,875 a year per client. The quality of life was expected to be considerably better, and it is.

But model plan costs continued to escalate the second year, not fall. Here are some reasons why:

Court records show that one expert consultant for the model plan, Gretchen Finke Patras, 25, of Minden, Iowa, turned in expenses, at \$300 an hour, including:

But model plan costs continued to escalate the second year, not fall. Here are some reasons why:

Court records show that one expert consultant for the model plan, Gretchen Finke Patras, 25, of Minden, Iowa, turned in expenses, at \$300 an hour, including:

- Four hours making banquet arrangements at the Doubletree Hotel in Tulsa.

- Four hours reviewing Doubletree catering information while on a plane trip to Tulsa from Iowa.

- Two hours preparing invoice.

- One hour preparing a comparison of costs in Nebraska vs. costs in Oklahoma for David Powell, former court monitor.

- More than five hours writing "thank you" notes to cast members for helping produce three model plan videos. The videos were to be training aids for state Department of Human Services employees.

Video production was halted after \$49,900 was spent without proper approval by DHS. Dan Broughton, a program administrator for the DHS Developmental Disabilities Services Division and liaison with the model plan, said the videos would cost \$20,000 more to complete.

Patras, in charge of the videos, was paid more than \$25,000 for services since January.

Broughton said cancellation of the videos would curtail consultant expenses, especially those of Patras and "two or three people out of Nebraska."

Other reasons:

DHS spent \$30,000 on medical expenses for Brian McKim before he left the model program and moved into his mother's home. McKim's mother said he alleges he was abused and neglected by direct care staff, resulting in injuries requiring spinal surgery.

Powell, model administrator and former court monitor, denies model plan employees were responsible for any abuse or neglect. He said he would defend the direct care staff in court, if necessary.

Powell billed the state \$4,692 for his legal consultation with a Tulsa attorney on the McKim matter in April 1990.

The state was billed \$955 in lease expenses on an empty house from March through May. Client Julie Paulson was to move from her parents' home into the house in

June. A one-time program development expense of \$8,769 included administration fees and furniture.

Costs are not the whole story of the model plan.

Remember Renee Parker? Renee is the 10-year-old who, placed in Hissom at birth, now lives with foster parents in Vian. Renee's progress and Robin Bullcock's progress are testimonials to the model plan and what can be accomplished in such settings.

Though the model spared no expense, its successes and failures weren't accessible to DHS workers — the people for whom U.S. District Judge James O. Ellison had hoped it would set an example.

He had recommended the model plan be undertaken in a very open manner, specifically designed to encourage and even invite evaluation and learning on the part of the defendants, interested parties, future vendors and the public.

It didn't happen.

"The model team was pretty much insulated," said David Goodell, DDSD program administrator.

Eranell McIntosh Wilson, DDSD administrator from August 1988 until she resigned May 15, 1991, admitted DHS learned little from the model plan.

"I think there are some lessons that have been learned," she said. "People recognize it is possible for people who have complex needs to go into the community. They know it from the fact that it happened."

DHS staff members were invited for initial model plan team meetings, Wilson said.

Powell said he quit sending meeting notices because of lack of interest of DHS case managers.

The model plan was in place before a Homeward Bound Review Panel was organized. The panel took the place of the court monitor, Powell.

The panel has reported to Ellison that there was almost no contact between the model program and the rest of the system.

"In fact, the relationships are, at best, strained between the two," the panel report stated.

The panel questioned the need for the level of case management being provided. At the time of the report, the model was serving five people in the community and had five people on staff in the model plan office.

The panel suggested if it were to serve as an example of what is possible and if it were to be compared with the rest of the system, that staffing levels should be comparable.

"Within the model itself, there seems to be a maldistribution of resources," the panel stated. "One man lives in a setting that could only be described as Spartan, with few wall hangings and decorations, and very little furniture. Another model consumer lives in a home, which is, by anyone's standards, very spacious, located in a very nice community, beautifully furnished, and tastefully decorated."

The panel reported that several very fine consultants had been brought in to work with either model clients or staff but had not been made available to DHS or class members not in the model.

Pat Wear II, review panel executive director, said the panel has had nothing to do with the model plan.

Wear said Powell suggested the model to the court because of his frustration with what he saw as other people's failure to provide services to the community.

"I've told David face to face the model was a bad idea."

MODEL PLAN PARTICIPANTS

- Robin Bullock, Tulsa.
Annual budget: \$234,269
Monthly rent: \$850
Staff salaries, benefits: \$145,534
- Mary Hardgraves, Tulsa.
Annual budget: \$104,307
- Frank Deaughty, Tulsa.
Annual budget: \$98,941
- Doug Berry, Tulsa.
Annual budget: \$116,340
- Julie Paulson, Tulsa.
Budget projection: \$99,774
- Renee Parker, Vian.
No projection.
Foster parents: \$40 a day
- Brian McKim, Tulsa.
Projected budget: \$53,659
(Note: Brian left the program in 1990.)

BB program
Recreation
Travel
Employment costs
Maj. eqpt. acq.
Miscellaneous
(clothing)
TOTAL EXPENSES
PROJECTED LAST MO.
CARRYOVER

BUDGET WORKSHEET HOMELIFE ASSOCIATION EXHIBIT B

PROVIDER AGREEMENT FOR Robin Bullock

Actual expenses through February, 1991,
and estimated for April, 1991

	Annual budget	Annual YTD	Actual last mth.	Projected this month
Alloc. carryover				- \$ 3,057.21
Court monthly all.				19,342.00
TOTAL				\$16,284.79
EXPENSES				
Salaries	\$125,460.00		\$9,659.38	\$10,455.00
Employ. Benefits	10,037.00		628.55	837.00
Retirement				
Payroll Taxes	10,037.00		764.83	837.00
FICA				
Unempl. Ins.				
Workmans Comp.				
Professional fees				
Rehab. and Educ.	\$16,500.00		223.50	1,375.00
Specific Assist.				
Medical	8,000.00		550.00	667.00
Dental	150.00			
Medicines	1,000.00		323.06	84.00
Food service	5,000.00		308.42	417.00
Shelter	13,150.00		850.00	1,096.00
Clothing Svc.	800.00			67.00
Transp. Svc.	1,500.00		60.48	125.00
Recreation	1,500.00		10.00	125.00
Testing fees				
Utilities	4,000.00			334.00
Insurance	150.00			
BB Prgm.				
Hskpg. Supplies	1,500.00			125.00
Equip. Rental	1,150.00		30.19	96.00
Furniture				
Equip. Purch.				
Miscellaneous	500.00			
Moving and Recrt.	500.00			
Maj. Property and Eqt.	1,000.00			
Equipment				
Administration	32,435.00		2,876.47	2,702.00
Janitor/other maintenance				
TOTAL EXPENSES	\$234,269.00		16,284.79	
LAST MONTH ALL.			\$19,342.00	\$19,342.00
TOTAL CARRYOVER			- \$3,057.21	

'Seeing all those perfect children' crushes mom of 2 with disabilities

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

Hearing other people talk about what their kids are doing depresses Sandy Ronk more than:

- Raising a son who has enormous physical and mental disabilities for 16 years and then giving birth to another son with similar disabilities.

- Her marriage falling apart after 20 years.

- Doctors who have never been able to tell Ronk why her sons have motor skill problems, can't talk and lack self-help skills to the point of needing 24-hour attention.

- Being denied adequate services from the Oklahoma Department of Human Services.

- Discrimination.

- Never getting a full night's sleep.

"Going to baseball, going to soccer, you know, and here I am going to therapists, doctors and EEGs, MRIs," Ronk said. "My whole life is spent doing that sort of thing."

Therapists, doctors, EEGs and MRIs are common terms for parents of children with developmental disabilities and mental retardation. Therapists, to help children gain motor skills, speech and language, self-help skills. Doctors, to handle the emergencies, monitor progress — or digress. Electroencephalograms to trace changes in electric potential in the brain, and magnetic resonance imaging to make cross-section images of the brain.

"I hate going to the pediatrician's office and seeing all these perfect children. That's, a lot of times, when I'll go home and cry."

But tears don't wash away the

problems. They just hurt. So does watching her children go without services from the state. Ronk is being told that their needs cannot be met because the state must spend its money to satisfy a federal court order to close Hissom Memorial Center.

Her oldest son, Jeremy, 19, has some autistic behavior, said Ronk, 42, a special education teacher in Tulsa. Jeremy doesn't interact with his environment. He withdraws from reality, typical of people with autism. Ronk's other son, Michael, 3, has the same kind of motor and speech problems, but doesn't appear to have the same autistic behavior.

"He likes to cuddle and be held and be happy," Ronk said. "He wants to be around people."

Both kids have to be fed, lifted and moved from place to place, although Jeremy can walk with assistance. Both are in diapers, and must be bathed and sedated to get them to sleep. Jeremy wakes often during the night.

Michael receives therapy through a cerebral palsy association scholarship, Ronk said. Jeremy gets therapy, too, paid for by the state. DHS also provides habilitation aides for Jeremy, 40 to 50 hours a week during the summer, less during the school year. He hasn't had a new wheelchair in five years. He has curvature of the spine and his chair will not allow him to sit up straight.

If Ronk goes anywhere, she must take Michael with her. Hab aides cannot care for him, only Jeremy. Ronk is applying for services for Michael, but she's heard he won't be accepted until he is 6.

"That's one of the problems," Ronk said. "So much goes to the Hissom kids and the community

kids are getting left out of a lot of things."

When Jeremy gets out of school, Ronk would like for him to have supported living and supported employment "and those are not available ... I've kept him with me all his life and I probably would longer but with Michael's problems ... I'd like for him to be on his own."

Hissom needed to be closed, though, Ronk admits. She worked at Hissom as a recreational therapy aide in 1967. She doesn't care for institutional care.

"I'm glad they're closing Hissom — I am glad. I don't believe that ... is the answer."

Ronk sometimes wishes she had placed Jeremy there "for just a few weeks so he could get all the services. But I'm glad I've always had him at home. I'm just a normal parent and he's just a child and that's the way you have to deal with it."

People need to realize that these kids are part of families and that they're loved, Ronk said.

"When Michael reaches out to get the toy, I'm just as proud as some other parent whose child hits a home run."

People need to look at the children and not the handicap, Ronk said. People tend to look at the weaknesses rather than the strengths.

Living without a man in her life has been hard, but, Ronk said, "what man would want me with two handicapped children?" It would be easier if Jeremy were out on his own and Michael could receive services.

"But you just have to keep going," Ronk said. "You just don't have any choice. You just have to keep going."

► THE LAW

Oklahoma statutes say any person who knowingly sells, furnishes or gives alcoholic beverages to an insane, mentally deficient or intoxicated person is committing a felony.

Those found guilty shall be fined no less than \$500 or more than \$1,000 or imprisoned in the state penitentiary for not more than courts as mentally retarded — your hands would be tied."

The owner of the 108 Bar, Beverly Liles, said her bar does not knowingly serve beer to anyone who is mentally incompetent. A bartender at American Bar, who refused to identify herself, said the bar does not knowingly serve beer to anyone who is mentally incompetent.

one year or be subject to both fine and imprisonment, said Jerry Henderson of Tahlequah, a state Alcoholic Beverage Laws Enforcement Commission agent.

"The law says anyone who has been adjudicated as mentally incompetent cannot be served," Henderson said. "A mentally retarded person never adjudicated by the

Handicapped language taints our perceptions

They still call them handicapped, disabled or mentally retarded. But those labels are objectionable.

"They are people, first," said Kathleen Kovach, Area II administrator for the Developmental Disabilities Services Division of the Department of Human Services.

Language reflects and reinforces our perceptions and misperceptions of others. All too frequently, the terms used for people with disabilities perpetuate stereotypes and false ideas, says Paul K. Longmore, Ph.D., Los Angeles.

This guide is offered as one means to unhandicap our language and thinking:

■ **Objectionable** — the disabled. This term sees people only in terms of their disabilities. **Preferable** — people with disabilities.

■ **Objectionable** — the mentally retarded, retard, simple-minded. **Rob** a

person of individuality by lumping people into one undifferentiated category. **Preferable** — people with mental retardation.

■ **Objectionable** — the deaf. Humanizing nouns emphasize the person. **Preferable** — deaf citizens.

■ **Objectionable** — the blind. **Preferable** — blind people.

■ **Objectionable** — cripple, crippled, cripp. No epithet is more offensive to people with physical disabilities. **Preferable** — person with a physical disability.

■ **Objectionable** — sightless, four eyes, blind as a bat. Those terms are inaccurate and demeaning. **Preferable** — blind, partially sighted, vision impaired.

■ **Objectionable** — confined to a wheelchair, wheelchair-bound, wheelchaired. Creates a false impression:

wheelchairs liberate, not confine or bind; they are mobility tools, from which people transfer to sleep, sit in chairs, drives cars, etc. **Preferable** — wheelchair user, uses a wheelchair, wheelchair using.

■ **Objectionable** — deformed. **Preferable** — has a physical disability.

■ **Objectionable** — lame, gimp, gimp. **Preferable** — walks with a cane, uses crutches.

■ **Objectionable** — vegetable, freak. **Rob** people with severe disabilities of their humanity. **Preferable** — the child has multiple or severe disabilities.

■ **Objectionable** — mentally ill, crazy, insane, psycho, nut, maniac. **Preferable** — mental disability, behavior disorder, emotional disability.

■ **Objectionable** — spastic, spazz. **Demeaning**. **Preferable** — has seizures, cerebral palsy, epilepsy.

In a pinch, quantity in staffing outstrips quality concerns

By DONNA HALES
and KRISTI FRY
Phoenix Staff Writers

Oklahoma woke up one day in October 1987 — the date a federal judge ordered Hissom Memorial Center closed — and discovered it needed direct care aides — lots of them.

U.S. District Judge James O. Ellison ordered the state to place Hissom residents, people with mental and physical disabilities, into the community so they could have a better life.

The order caught Oklahoma surprised and shorthanded. Surprised — because the state felt it was adequately caring for its citizens with disabilities, and, because it didn't expect to lose the Hissom lawsuit. Shorthanded — because it had few trained habilitation training aides, people qualified to live with and care for mentally and physically disabled people day and night, if necessary.

The Oklahoma Department of Human Services sent out the call for help. People on the unemployment rolls and off the street flocked to make application as direct care aides. Qualified applicants were a rarity, but DHS had no choice.

It had to hire — and training had to become a priority.

The state has trained more than 7,000 direct care aides, said Shirley Ryan, director of Human Resources Development for DHS.

Therapeutic Concepts Inc., a private Florida firm, also trained some direct care aides, she said. TCI trained 5,000 employees, but many never intended to work as direct care aides, Ryan said. Some were direct care staff in state institutions and others were DHS division employees.

Only about 3,000 of the direct care aides are working for supported living provider firms, Ryan said.

The direct care aides were trained not only to care for Hissom clients moving to the community but for employment in intermediate care facilities for the mentally retarded across the state, for use in nursing homes and schools, as respite workers, foster care workers and as institutional workers, Ryan said.

She said an exact number of direct care aides and where they are working isn't available because her unit has no adequate tracking system.

"One little PC doesn't get it," Ryan said.

Results of that training, four years later, have left much to be desired, according to mental retardation experts.

"The quality of training the state has offered is not even mediocre," said David Powell, former court monitor assigned to oversee DHS compliance with the Hissom settlement agreement. Training supports are "significantly deficient."

The state's direct care staff training does not appear to result in significantly increased knowledge, improved values, or a change in behavior, Powell stated in a recent report to the court. The day-to-day capacity of direct contact staff to build and reinforce positive behaviors is needed.

When complications present themselves, too many direct care staff members don't take responsibility for addressing the complications, but refer the client to a psychologist, Powell said.

Powell placed the blame on DHS's shoulders.

DHS denied there is a major training problem.

However, firms that have hired direct care aides trained by DHS also have complained to the Homeward Bound Review Panel, a three-member group appointed to take over Powell's court monitoring duties.

The panel's last formal report to Judge Ellison listed these training concerns:

? Three separate training curricula — one from Rutgers University, one from Therapeutic Concepts Inc., and one used by the model program, a program initiated for seven clients and administered by Powell.

? The number of staff members being trained in a national system of crises intervention that calls for physical intervention by the worker.

? Qualifications and orientation of staff providing training in vo-tech schools.

Some of the material does overlap, said Dan Broughton, a DHS programs administrator who acts as a liaison between DHS and the court parties.

Pat Wear II, executive director of the review panel, said there is probably too much content in the state's training. It's "very technical. All that stuff you would do if you were training someone to work in an institution."

Broughton said DHS is going to revise the courses.

Wear said Oklahoma has a good training program — not the best — but the state requires more hours of training than other states, and that's appropriate, he said.

More value training is needed, "where people embrace what this is all about," Powell said.

The national crisis intervention system of training was defended by Eranell McIntosh Wilson, administrator of the DHS Developmental Disabilities Services Division until she resigned in mid-May.

Training consists of 16 hours, 90 percent of which is positive, vocal, how you calm a situation down.

"You redirect people to other activities," Wilson said.

The other 10 percent involves direct contact.

"If a client comes at you with a chair, how do you keep from getting your brains knocked out?" she said. The training is supposed to ensure the employee won't get injured and the client won't get injured.

"Some people over-utilize the 10 percent they learn," Wilson said.

Most direct care aides were trained through 36 state vo-tech schools, Ryan said. Some paid for their own training. Many received training under the Job Training Partnership Act, she said. DHS reimbursed some provider firms offering training.

Wilson also defended training by the vo-tech system.

"Vo-techs are in the business of educating people," Wilson said. "They've been doing it for years."

Quality assurance teams, which will sit through classes and see whether instructors can put over the information, are planned, Wilson said.

"There are some people with a Ph.D. and seven other degrees who don't make good teachers," she said. "To say there are some bad teachers — there are some bad teachers at the University of Oklahoma, Harvard, Notre Dame."

Louis Bullock, plaintiffs attorney in the Hissom lawsuit, echoed criticism of inadequately trained staff members.

The solution appears to be to assign two inadequately trained staff members to the task, he chided.

"We'd be better off to hire one person and pay them so we could get somebody qualified," Bullock said.

The state pays for-profit firms \$8 an hour to supply direct care aides, including benefits. Direct care aides' wages, depending on the firm for which they work, receive anywhere from minimum wage to \$7 an hour.

The cost of training the workers hasn't been calculated yet, according to a DHS report setting out Hissom-related costs that was released in June.

Rape, neglect among 44 abuse cases

By KRISTI FRY and
DONNA HALES
Phoenix Staff Writers

One Hissom Memorial Center client placed in supported living has been raped, another allegedly beaten and neglected over the past two years, the Muskogee Phoenix has learned.

In addition, more than 40 other abuse allegations have been lodged by Hissom clients in supported living in 11 months of fiscal year 1991, according to the Department of Human Services.

The DHS denied access to details of the confirmed abuses, citing client confidentiality.

There are 174 Hissom clients in supported living in the community. Under a federal court order, Hissom is being closed. All remaining residents, 276 as of June 1, must be moved into the community by October 1994. Other former Hissom clients will be moved out of nursing and group homes and small intermediate care facilities for the mentally retarded.

Details of the rape and alleged beatings:

■ The rape of a 26-year-old developmentally disabled client by her 27-year-old direct care staff worker. A charge of first-degree rape by force or fear was filed in Tulsa County District Court in September 1990.

Tulsa County prosecutors dropped the rape charge four months later only when a psychologist advised testifying would be too traumatic for the victim, said Chuck Richardson, assistant district attorney.

DHS contracts with community provider firms require background checks on habilitation training specialists, said Dan Broughton. He is a DHS programs administrator who is liaison with the DHS Developmental Disabilities Services Division (DDSD) and the parties in the Homeward Bound vs. Hissom lawsuit, which resulted in the order to close Hissom.

"In that one, there was a lack of a background check," said Bill Sagona, the guardian ad litem who represents the victim.

The alleged perpetrator no longer is working with the Hissom class clients.

"They let him go, I know that," Broughton said. "They ran him off."

■ Brian McKim, 32, non-verbal and multi-handicapped, was beaten by direct care workers and neglected after he moved from Hissom to an apartment in Tulsa.



Kovach

Betty McKim said when her son lived at Hissom he was active and could take care of himself, even moving from his wheelchair to bed. She would take him to the lake and camping on weekends. He

was active in Special Olympics and would go bowling.

He had a pouch on his wheelchair and delivered the campus mail five days a week, propelling the chair with his feet.

Hissom employees said he was loved and was loving in return. He moved to Hissom when he was 10.

When he was convinced Hissom would be closed, he agreed to enter a model plan established for seven Hissom residents. The model was supposed to serve as an example to show how people with

developmental disabilities and mental retardation could be integrated into society.

Brian moved into a Tulsa apartment in June 1989. He required one direct care worker around the clock and two workers until bedtime, his mother said.

"He had many, many, many falls — he was physically abused, neglected and left in a urine-filled bed most of the time," Betty McKim said.

Brian was in the supportive living placement until Nov. 5, 1989, when his mother removed him to her home.

"His bodily functions had decreased to zero. He couldn't even roll over. He couldn't sit up. He couldn't move his legs. He couldn't open his hands."



Powell

Brian can't speak. He related the alleged mistreatment to his mother and Tulsa attorney Robert Butler through help of a speech therapist.

"We got a lot of" things out of him that day . . . I mean he told it," Betty McKim said. "He told he was tied up in his wheelchair, even over the weekend from Friday to Sunday. They took him to bars. They hit him with their hands and they were even mean to him when he was in the bathtub bathing."

On Oct. 25, 1990, direct care workers took Brian to a Tulsa hospital. His ear was almost cut off, said Betty McKim.

"They told me they were transferring him from one wheelchair to the other and he fell against the TV. He fell so hard that it broke the table the TV was on and actually cracked the hard case on the TV."

At the time, her son was supposed to be using only his therapeutic wheelchair, she said.

Brian underwent spinal surgery in January 1990, and has to be cared for as if he were a baby.

David Powell, administrator for the model program and former court monitor in the Hissom case, said there has been an investigation by the DHS Adult Protective Services Division. DHS officials said investigations of that division are neither confirmed nor denied.

Powell denies any employee in the model plan mistreated Brian, saying he will defend his people in court, if necessary.

Butler said somebody may have to. He plans to ask DHS to make a full investigation of the alleged incidents involving Brian.

Although Powell denies that Brian was mistreated while he was in the model program, he said "there is abuse about any place that people are caring for people."

In a court monitor report, Powell said he visited one particular client several times in the evening over a span of a few weeks and found the client alone at least three times. Direct care staff members were supposed to be with her at all times.

"It's hard for me to imagine a staff person leaving without the following staff person there," Powell said.

There is no central reporting requirement to assure the person on the next shift shows up, said Kathleen Kovach, DDSD program administrator in Area II, which

Reporting abuse

Department of Human Services made the following investigations of reported abuse, mistreatment or neglect to clients:



Definition of terms:

Abuse - intentional harm.

Neglect - similar to abuse, difference being intent.

Mistreatment - breaking a rule which could result in harm to client.

Exploitation - taking advantage of client in some physical manner.

Institution

	Fiscal '88		Fiscal '89		Fiscal '90		First 11 months FY 91 *		
	Investigated	Confirmed	Investigated	Confirmed	Investigated	Confirmed	Investigated	Confirmed	Pending
Enid State School	56	15	60	10	98	22	96	10	33
Pauls Valley State School	81	28	82	20	34	6	43	7	8
Hissom Memorial Center	103	20	85	25	77	17	51	15	12
Hissom clients living in community	0	0	0	0	0	0	44	7	16

Source: Office of Client Advocacy, Department of Human Services

Graphic by Joan Morrison

encompasses 19 counties, including Tulsa.

The provider firms are charged with making sure the staff is at work, she said.

How often do those charged with caring for the mentally retarded in the community turn perpetrator and inflict harm?

No one really knows. Some Hissom class clients in the community can't speak. Some are proficient in sign language, while others communicate only with a smile or frown.

Guardian ad litem Sagona, who represents 245 Hissom class clients, said in May he believed about six of his 106 clients living in the community had suffered abuse.

"It's way less than 10 percent," he said.

Abuse of Hissom class clients in the community usually comes from those who work with them, Powell said. The incidents aren't

"across the board — some providers have better skilled personnel than others."

Abusing caregivers of people with mental retardation now can move from program to program, generally without detection, said Chase Gordon, administrator of the Office of Client Advocacy. The DHS office investigates abuse.

Background checks would not necessarily show prior improprieties with clients, a report from Gordon's office reveals. Private agencies may be reluctant to report the reason for separation.

The Homeward Bound Review Panel, comprised of three out-of-state experts in mental retardation, has issued a report to U.S. District Judge James O. Ellison advocating clients be told of the backgrounds of provider firms who operated in other states before coming to Oklahoma.

Client can't go back — even for his own good

By DONNA HALES
and KRISTI FRY
Phoenix Staff Writers

Life after Hissom has placed a heavy burden on Donnie Wilson.

Wilson, 23, is a person with mental retardation aggravated by severe behavioral problems. He was removed from Hissom Memorial Center where he'd lived since age 7 and relocated into a Tulsa neighborhood in 1989.

Living in the community has been violently tempestuous at best, incidents occurring since his move illustrate. Wilson wasn't prepared to cope in his new environment. His case is an example of how the state's emergency support system for Hissom clients has failed.

According to Tulsa County District Court records, Wilson was:

- Arrested Sept. 7, 1990, and charged with first-degree arson after setting fire to his rented home. Damage is estimated at \$12,000.

- Frustrated with a VCR he had rented on Feb. 2. Wilson threw it across the room, verbally abused staff members and ripped his phone from the wall.

- Upset on Feb. 19. He threw furniture and damaged his direct care staff's automobile.

- Treated at St. Francis Hospital in Tulsa after ingesting a handful of Tylenol April 12 while at his work training site.

A Tulsa judge in Wilson's arson case remanded him to the custody of the Oklahoma Department of Human Services for assistance, pending an October 1991 hearing.

DHS assisted Wilson's move into the community in the first place. The move also was sanctioned by a federal court monitor reviewing placements of Hissom clients into the community.

Dr. Robert A. Nicholson, a Tulsa clinical psychologist, submitted a report on Wilson to the state court, concluding he didn't believe Wilson could assist in his own defense of the arson charge.

Wilson had told Nicholson he didn't believe the arson charge was serious — and that he didn't see why he should have to pay his landlord any money since all he did was set his own furniture on fire.

Wilson was moved into the community "without learning responsibilities, such as realizing natural consequences for his actions and the responsibilities that accompany rights enjoyed in the community," a report filed with the state court by Wilson's habilitation team stated. Such teams include Hissom clients, their families, and professionals and direct care staff members who work directly with clients.

Now, Wilson is under 24-hour direct supervision of

Donnie Wilson was moved into the community "without learning responsibilities, such as realizing natural consequences for his actions and the responsibilities that accompany rights enjoyed in the community."

— Wilson's habilitation team

two habilitation training specialists while living in the community. But the provider agency that hires Wilson's staff has had turnover in management and home staff. There is confusion in maintaining consistency in staff and conformity of Wilson's program, according to the team report to the state.

"In each instance of a major behavioral problem, it was determined that Mr. Wilson's behavior plan and IHP (individual habilitation plan) were not followed," the report stated.

Wilson is to receive psychiatric monitoring monthly and psychological counseling twice a week.

Yet, Wilson's behavioral problems place him medically and physically at risk, said another report to the state court by Dr. Diane H. Williamson, a behavioral specialist.

Wilson's staff and others may be injured, Williamson said. "Physical intervention carries the risk of injury to client and staff."

Wilson has a seizure disorder and is insulin dependent. He has been diagnosed as mentally retarded as a result of a diabetic coma suffered when he was an infant.

Nationally recognized intelligence tests place his mental age between 6 and 8 years. Another test reflects an adaptive behavior composite of 10 years and 9 months.

Refusal of food and medications places Wilson at risk of a diabetic coma. Longtime noncompliance could cause loss of vision, vascular disease and renal failure, Williamson said.

Even though Wilson's move to the community was premature — and even though he isn't getting the court-mandated community support he needs to ensure the safety of himself and the public, he has to stay put.

Wilson can't return to Hissom to learn coping skills in the more structured environment. Because of the federal court order, once a Hissom client leaves the institution, there's no going back.

Bullock: Serve all with bigger pie

By DONNA HALES
and KRISTI FRY
Phoenix Staff Writers

TULSA — Attorneys Louis Bullock and his wife, Pat, filed suit on behalf of a group of parents of children living at Hissom Memorial Center in May 1985 because the parents claimed their children were being mistreated and denied adequate services.

As the battle began, Bullock soon learned that he was facing a bitter struggle against the Oklahoma Department of Human Services, parents of other Hissom clients, and a society that has historically segregated and discriminated against people with developmental disabilities.

In 1987, a federal judge ruled for the plaintiffs, and the Bullocks had won the battle. A settlement was reached in the case in 1990. Today, the Bullocks are still fighting the war. In an interview, Bullock responds to questions about what has occurred since the suit and what the future holds for Oklahomans with developmental disabilities and mental retardation:

Q: Since implementation of the court order to close Hissom, millions of dollars have been spent. Is the state getting its money's worth?

A: Yes. There's no question this stuff has been costly. No one has worked harder at being sure that the costs were minimum than Judge Ellison (James O., the federal judge who presided over the Hissom lawsuit). There is a lot of concern that we get the most bang for the buck. It is going to be addressed.

We spend \$600 a day to lock up severely disabled people at the Greer Center (a unit for people with mental retardation and mental illness at Enid State School). In the Hissom case we've taken a few of those people out and have them in community placements for significantly less. No one! No one criticizes spending that type of money to lock a person up. You spend that kind of money to put them in the community where you give them a better program — everybody goes into hysterics about it — they want them out of sight. I think there are some things we ought to do on the money, but that's not what's going on here, that's not what the real debate is. The folks who are raising the challenges about the money, they clearly have another agenda and it's not to make this a leaner and more efficient program.

Q: Do you feel all institutions for people with mental retardation should be closed?

A: There's no question that we can deal with the problems out of the institutions. Hissom is not licensed in terms of providing medical care to do anything that you can't do in your own home and that in fact families today do in their own homes. The complexities of institutions are just the opposite of what the clients that we've housed there need. Part of the reason those places fail is that to succeed in an institution, you have to have the ability to manipulate the institution. ... These folks have very specialized needs on the front end, and by and large have few

"It is philosophically the wrong thing to do and technologically it's \ the wrong thing to do. You've got to get them out of the institutions." —

Louis Bullock Homeward Bound attorney

skills with which to manipulate an institution. So, in fact, they don't thrive in the institution, they do just the opposite. They begin to wilt and withdraw.

It is philosophically the wrong thing to do and technologically it's the wrong thing to do. You've got to get them out of the institutions. That's going to mean that for some clients you're going to have very expensive programs. But that's very, very, very few. Most of the clients will go on to be highly independent and a number will be in some type of semi-independence.

All of that will be much cheaper for us. Even those that are advocates of that look at those few extreme cases and say, "Certainly, you need institutions for these folks." What that assumes is that we're going to keep 300 folks out there because three people need that level of care. The economics are all backwards in doing that. You're better off to go ahead and say, "OK, we're going to get everybody out." Some of these folks are going to require very high cost programs. Where you have people who have limited communication ability, it's too easy to write them off — not knowing until you get them out and let them make choices. Not one person experienced in this field has ever come forward and said Hissom should be kept open.

Q: Was the Homeward Bound vs. Hissom lawsuit for social change or for client damages?

A: Social change. It was only to cause the state to change the way it's serving people. What's fair is for the state to do what we brought the suit to cause the state to do. And that is to develop a system of care based on this model throughout the state. One of the first things that Judge Ellison asked was, "What about everybody else?" The answer was that we want to bring this lawsuit to reveal to the state what's wrong with locking people up and to show the state that there really is a better way to treat people and that it can be done in a reasonably efficient manner.

—Q: How long must parents of children with developmental disabilities and adults with developmental disabilities wait before the state offers similar services to them that it offers to the Hissom class?

A: All I can do is use the tools the law gives me. The law hasn't given me a good tool to reach the folks you are talking about. What I've tried to tell the state, though, is that they can avoid our going after Enid and Pauls Valley (state schools for people with men-



tal retardation, which Bullock has threatened to sue to close) if they will make this a system for the entire state, open to everyone. Then, we can wait on that in terms of being all encompassing.

Q: Do you have faith in the state accomplishing that goal?

A: No. I don't have a lot of faith in terms of the state having a great, warm heart, which is all of a sudden going to embrace these folks. That's not the nature of the beast. I do believe the state would like to avoid the spectacle of legal challenges against Enid and Pauls Valley. We're willing to talk about how to avoid those. My confidence that we can do something arises out of some belief that the state will act in what it perceives to be in its own best interests as an institution. I don't think the folks I've seen making ultimate policies, most of those will not do this out of some goodness of their heart. There is a good chance they will do it out of a pragmatic view — meeting those needs saves you significantly down the road.

Q: Why hasn't the state put more emphasis and resources into foster care for some Hissom clients instead of most of the money going into supported living programs?

A: One of the things the state has not developed, the best bargain of all, is a good foster care system. Instead, they nickel and dime these families, providing fewer supports than they provide to anyone, in

spite of the fact that that's really a resource that needs to be nurtured and built on. A good foster program is better for the client, it's cheaper for the state. Instead we've spent enormous sums of money almost exclusively in supported living, which is an important program ... but there are other models ... which ought to be worked with.

Q: There are behavioral challenges with some people with developmental disabilities from Hissom. Are those people and the general public at risk?

A: No. But there are real concerns. Several things need to be done. One is patience. We've taken folks out of an institution where that type of behavior was tolerated. In fact, it was rewarded because these clients learned how to manipulate the institution by doing that type of stuff. It was good, successful behavior for them. Now, we have them out in an environment where what they've learned isn't working very well for them. We need a better emergency response system. But because in homes across the nation there is abuse, that is what's going to happen in some of these clients' homes. Now, it also happened with alarming frequency at Hissom. ... Our ability to detect the abuse and to stop it will be better in the community than it was in Hissom.

Q: A key component of the system is a client choice provision. What does that involve?

A: That is one of the things which this system has been praised for nationwide. It gives individual clients a lot of leverage in making providers respond to them rather than the provider making the state happy. Making the state happy is not always synonymous with making the client happy. Providers in Oklahoma may lose clients because they fail to meet the clients' needs. That's a real healthy dynamic which I expect will become stronger.

Q: What about ail the bigots in the world? Will people in the community accept persons with developmental disabilities in their everyday lives?

A: Bigotry is a problem. We need to admit it and we need to address it, but the answer to security is not isolation. ... We're now fighting the fight with the schools. Those places have to do better. But what we know is ... the kids are beginning to integrate in real positive fashions. ... Boy, you don't have to be in this work long before you realize that the real problem for the disabled is the deep-seeded prejudice against them. It's far worse than many of their disabilities.

It's a huge task. It is probably no less or no more than we faced with our-African-American citizens. So it's not going to be done overnight. But I'm convinced that it's a doable task. As we integrate the schools and students grow up knowing and having friends who were disabled they won't be afraid of having a disabled person live next door, or selling them clothes down at the store, or having dinner with them. But until we get over the "these" people or "those" people syndrome, it's going to be a real challenge.

Demps: State must come to grips

By DONNA HALES
and KRISTI FRY
Phoenix Staff Writers

OKLAHOMA CITY — Benjamin Demps Jr. took charge of the Oklahoma Department of Human Services in February. It didn't take long before he learned DHS was under a court order to close Hissom Memorial Center at Sand Springs, its premier institution for the care of people with developmental disabilities.

DHS is Oklahoma's largest agency, with 13,000 employees offering a wide range of services to the state's needy. Historically, the state has segregated and discriminated against people with developmental disabilities. The court ordered Hissom closed and its clients moved into supportive living in communities across the state.

The court's intention is for Oklahoma to use Hissom as an example of what should be done for all people with developmental disabilities. In an interview, Demps explains his philosophy and offers some insight into what direction his agency will take:

Q: When will DHS provide services for the more than 570 people with developmentally disabilities on a waiting list who are not a part of the Hissom class?

A: When we're funded for it.

Q: Is funding the only obstacle to servicing everyone?

A: No. The federal mandate to close Hissom has been a very high priority. Within that consent decree, there is an approach to the care of service provided to the developmentally disabled and the mentally retarded which has yet to reach a conclusion.

We're proceeding along with Hissom:

(1) Because we have a court decree that says we have to do that; and

(2) We have to figure out what we're going to do. We've got to remember that the state of Oklahoma had not had an acceptable vision of how it wanted to provide care for this kind of client.

We've been shown the way by the court, although many people would disagree with that.

It's clear that not just with Judge (James O.) Ellison's decree, but around the nation there is a clearly focused movement toward supported living. So we have to come to grips with that and how we want to handle that in this state and get some idea of the costs, that is the long-term costs, the rationalized costs. So we have a transitional period going on here.

I'm faced with a whole state that needs. ... I want to come out of Hissom with a rationalized public policy. So I asked the (Hissom review) panel to work with me to do two things:

(1) Help me contain costs so we can have some sense of what we're doing here and we can use this

"Someone said, 'Well, we had to do that because the court said'... Well, the court did not say do things foolishly."

— Benjamin Demps Jr. DHS director

period as an indication of what's possible.

(2) Then using the panel's knowledge and its view of things, plus our view, make this period a bridge to the future. And they agreed.

Q: What is your game plan?

A: I am about to make some changes — organizational changes. I'm going to selected cities to do what I call a DHS report card, to say here's what DHS does. There's a good deal of concern and interest of those who have loved ones, family and friends who receive services with respect to developmental disabilities and mental retardation. There are thousands more Oklahomans who know nothing about the situation.

Therein lies the crux of my approach because while there are certainly those who will be proponents of increased levels of care, and more up-to-date methods of care, the cost of that care is something most Oklahomans are going to have to be well informed on if they are going to continue to support that care through tax revenues.

Q: Why weren't expenses in the Hissom transition questioned by the DHS?

A: It may just have been an inadequacy of management attention and tied in with some amount of feeling that, well, the court says, the court says, the court says. ... As I began asking questions (about Hissom) someone said, "Well, we had to do that because the court said," and that becomes the rallying cry — because the court says do it. Well, the court did not say do things foolishly.

Somewhere along the line, someone should have sent the court the money and then gone to check with the court about those expenses.

I need to change, shore up the processes so that these things become automatic, whether you're gun shy or not, whether you're court shy or not, that there is no question that when a bill comes, someone must have looked at it, someone else is checking to see that audits and reviews are done even on those things.

Q: What are you going to do if someone sues to close Pauls Valley and Enid state schools for people



Benjamin Demps Jr.

with mental retardation?

A: We have to realize that as time moves on, we still have to work toward providing community supported living type situations for those in Enid and Pauls Valley.

Now, there's still another question that cannot be ignored. When I voice this question, I'm not voicing some problem with the court consent decree and order. There are many people who believe there are clients who will not, for various reasons, be suited to community living. There are some who believe that some amount of institutionalization is necessary.

There's nothing in life that is all off and on, white or black. There's all kinds of shades of gray and in between. So some of those troublesome issues have to be thought about. They're best thought about in a public way. The public has got to participate.

Q: Do you think money is being wasted in the Hissom transition?

A: Oklahoma did not give a sufficient amount of care to the Hissom focus class — did not. And citizens of Oklahoma sued the state of Oklahoma about that and the state fought it in court — standing up — and lost. The wisdom of the decision — the wisdom of the

consent decree is really not for me to question at this point because we are under order of the court and as yet I have not seen anyone in this state willing to go back and ask for a reargument of that.

We've got two problems here and that's why I say I take the public policy approach. Rather than fight Hissom, Hissom, Hissom, Hissom, sit down and say: "Well, what then is the right thing to do. Is it all going to be community-supported living or is there some class of people, however you define it" ... but one cannot argue that in the Hissom instance without going back to court because we lost. That's why I like the approach of let's look at the cost because it has to make sense for the future. One thing that was not said was let's look at the philosophical approach of putting everyone in community supported living or some not in community supported living.

Q: Why did Oklahoma hire, for the most part, out-of-state consultants to help establish a supported living System in the communities?

A: The state doesn't grow its own experts in mental retardation. . . . We don't have any mental retardation experts growing up in Oklahoma. They're not taught here . . . we don't have any experts in human services administration. . . .

So if we want to do it we've got to go outside the state to get them or else we face what we faced prior to Hissom, thinking we're doing our best . . . I don't think there was any evil intent back then. People thought they were doing what was right. But they didn't know.

Q: Are we just a bunch of dumb Okies?

A: No, this state is not unlike other states. Other states are getting sued and other states are getting kicked in the butt, too. What we're talking about here is a society that changes faster than we change.... If we had a University of Michigan or University of Illinois or one of the big universities that had dedicated themselves to developmental disabilities we would have been way ahead of the pack. It happens that we haven't given our attention to it.

I think we're at the test now. If we don't move along smartly now somebody might want to use that phrase four years from now because really it's right before us if we don't meet it head on and say, what are the problems? What are the conditions? What makes sense? How can we avoid the accusations pre-trial and at the same time do the reasonable, right thing? But you have to look at it and you have to be willing to change. And in order to change I believe people have to be informed. I wouldn't think of waking up tomorrow morning and saying, OK state, here's the way we're going to go. That's crazy. I wouldn't accept it if I heard it and no one else would either. We've got to talk about it.

State can get more funds — if it spends more

By DONNA HALES
and KRISTI FRY
Phoenix Staff Writers

Oklahoma got permission from the federal government Wednesday to access more federal dollars over the next five years to serve people with mental retardation living in the community.

There's one drawback: The Legislature and the governor would have to appropriate funds to buy those federal Medicaid waiver dollars. The state must pay 30 cents of each dollar spent.

Oklahoma did not access all the Medicaid waiver funds the federal Health Care Financing Authority, a division of the U.S. Department of Health and Human Services, would have allotted Oklahoma in 1991 — \$23 million.

Because of Oklahoma Department of Human Services' budget restraints, only approximately \$9.5 million in waived funds were accessed, said David Goodell. He is program administrator for the DHS Developmental Disabilities Services Division (DDSD).

Most Medicaid programs are entitlement programs and the state is not limited as to how many it can serve or how much it can spend, Goodell said.

The special Medicaid waived funds are so termed because states have to "engage in lengthy, elaborate and sometimes painful

negotiations with the Health Care Financing Authority" to gain more latitude to spend Medicaid funds to meet individual needs, Goodell said.

The waived funds are spent on:

- Habilitation training specialists (direct care staff).
- Respite care.
- Transportation.
- Architectural modification (making homes accessible to those in wheelchairs).
- Foster care.
- Professional services including physical therapists, speech therapists, occupational therapists and psychological services.

Next year, nursing services can be included, Goodell said.

Of the \$9.5 million spent in 1991, approximately 825 people were served — 265 former Hissom class members received approximately \$4 million in waived services and 560 people with mental retardation who had never lived in Hissom shared approximately \$5.5 million in waived services, Goodell said.

Oklahoma could access \$35 million in Medicaid waived funds in fiscal year 1992, which would serve more than 1,100 people. But the DHS budget only calls for \$14.7 million in Medicaid waived funds to be accessed in fiscal year 1992.

The five-year renewal authority received Wednesday would allow Oklahoma to access \$87 million a year within five years to service up to 2,001 people, Goodell said.

"That's a significant increase in what they will allow us to spend," he said. "But we've got to get the Legislature and the governor to appropriate sufficient funds to spend that money."

Jim Nicholson, interim DDSD administrator, said Oklahoma doesn't have a supported living program capable of serving its population of mentally retarded people.

The Medicaid waiver is helping Oklahoma get closer, he said.

The making of this series

Two Muskogee Phoenix writers drove several thousand miles and conducted more than 120 interviews during a three-month investigation into the state's efforts to close Hissom Memorial Center.

The result was a five-part series titled "Life After Hissom" that concludes today.

It was a story begging to be told.

Many people the Phoenix interviewed, from Muskogee to Pauls Valley to Tulsa to

Oklahoma City and other communities across the state, were eager to talk about what they perceived as excessive spending and preferential hiring and contracting procedures.

Parents of Hissom residents expressed fear for their children being moved into the community; others praised the move, saying it was time to close Hissom.

Still other parents, whose children are not receiving needed services from the state, were anxious to vent their frustrations with the system. Some cried when discussing their painful struggles and the injustice and guilt they feel because

neither they, nor the state can provide what their seriously ill children need.

Department of Human Services employees — from administrators to the rank and file — abhorred the waste of taxpayer funds and the fact so few people with mental retardation were being served.

They railed against the lack of oversight by the few who had the power to demand documentation before tax money paid the bills — bills so scanty that more than \$90,000 in a two-week period for consultant fees and professional services could be tallied on two sheets of paper with no ac-

companying time sheets or invoices.

The Phoenix obtained copies of hundreds of pertinent contracts, reports, memos and other documents. Help came from legislators and those affiliated with Hissom and others involved in community programs for persons with mental retardation.

The Phoenix also pored over thousands of pages of documents and orders that make up the Homeward Bound vs. Hissom suit in U.S. District Court in Tulsa.