



UPI telephoto

Charlotte Knighton takes her son, William, to federal court in Philadelphia on Friday to testify in the hearing on whether to move 80 mentally handicapped children from the Pennshurst Center for the Mentally Handicapped. I

Plan to close Pennhurst stirs emotional opposition

By Denise Foley
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PHILADELPHIA — Terri Lee Halderman's soft giggles rippled across the packed courtroom, rustling a few heads and catching the mild attention of U.S. District Court Judge Raymond Broderick, who made no move to gavel her into silence.

A gavel wouldn't do it.

For Terri Lee Halderman, only kisses work.

Terri Lee held out her cheek for a peck from her mother, Winifred Halderman of Yardley, who grasped the small, teasing hands firmly in hers.

Terri Lee, who later dozed noiselessly during Friday's court proceedings, is 25 years old.

Suit filed

Profoundly retarded, she was the focal point of a suit filed by her mother five years ago charging Terri Lee, then 21, was receiving inadequate treatment — because of lack of staff and funding—at the Pennhurst Center for the Retarded in Chester County.

That suit, to Mrs. Halderman's dismay, led to a court ordered plan to close the institution and place its 1,040 residents in community homes and facilities in Bucks, Montgomery, Chester, Delaware and Philadelphia counties.

Over 50 parents of Pennhurst residents, some with their children, packed Judge Broderick's courtroom Friday to oppose a plan to move all of the school-age children from Pennhurst by Sept. 1. Staff and parents picketed outside the federal courthouse at 6th and Market streets here during the proceedings, which will continue tomorrow night at 6:30.

Their fears were expressed on the stand by Judge Edward Bradley, president judge of Philadelphia's Court of Common Pleas, whose 14-year-old daughter, Michelle, is a Pennhurst resident, and who is, he says, getting fine care.

"My concern," he told Judge Broderick, a person friend, "is that we're talking about facilities that don't exist, a staff that doesn't exist. . . . We're doing a lot of talking, but if the facilities and resources are not there, I don't see this as an improvement or substitute for Pennhurst."

Broderick responds

Broderick, in an impassioned response, assured Judge Bradley that "absolutely no person is going to leave Pennhurst unless their lot is going to be improved.

"The bottom line, judge, the bottom line is that we want to give the residents of Pennhurst a better life and the chance to reach every opportunity God wants them to have," Judge Broderick said. "When we're dealing with God's children, nothing is too good."

But the truth, Pennhurst parents say, is that the Sept. 1 deadline is unreasonable, that facilities for the youngsters — 61 of them, none from Bucks County — do not now exist and cannot be arranged by that time.

Other experts testified Tuesday that appropriate facilities, and most importantly, services for the 61 youngsters, most of them severely retarded, cannot be developed by the Sept. 1 deadline.

Other concerns

That date, Judge Broderick assured them, was only set to prevent county officials from continuing to "drag their feet" on setting up living arrangements and programs for the children, all under 21.

But parents like Winnie Halderman have other concerns. Terri Lee, who is now at the Woodhaven Center, functions on the level of an 18-month-old child. She would not survive, her mother said, in an apartment or group home setting.

Like boarding homes for the elderly and mental patients, recently under fire, the community home settings are not operated by professionals, are not licensed and have no official standards.

Limited consciousness

Terri Lee, who broke her jaw in three places and broke a toe when left unattended at Pennhurst, needs almost constant supervision, particularly at mealtime. She has no teeth because of the jaw injury and no gag reflex. She often chokes. Brain-damaged at birth because of the Rh factor in her blood, she also has cerebral palsy.

And, like many of the profoundly retarded, Terri Lee cannot speak. With her scarcely focusing eyes, she is a limited consciousness, a being hidden behind a thick mist, barely reachable.

"I'm frightened to think of her in an apartment," said Winnie Halderman, a plump, resolute woman with thick, steel-gray hair. "She's very vulnerable. And people out there are very cruel. I wouldn't want her to be abused by any sex maniac. They need protection. When

we say that, they call us emotional parents. But the world out there is cruel. They need protection and we have to give it to them."

Mrs. Halderman's fears, like those of the other parents, are not without substance.

Polly Spare of Doylestown, the mother of two retarded children and a member of Bucks County's Mental Health and Mental Retardation board, is a certified advocate for several Pennhurst residents in other counties.

Certified advocates are appointed for those residents who do not have families, like 53-year-old Teddy Thomas, the Pennhurst residents who garnered headlines by his adamant refusal to leave the institution. He is now also represented by an attorney, Pam Cohen, who sat in on Friday's session.

Parents alarmed

Mrs. Spare, a tall, formidable woman of the Bea Arthurilk, said some of the higher functioning Pennhurst residents already released into the community have had experiences that alarm the parents of the more severely retarded youngsters.

She cited the recent case of a man released to a group home in Philadelphia who was returned to the hospital within a week with third degree burns of his legs. Some of the other former Pennhurst residents living in community settings have overdosed on their medication, which, in many cases, is self-administered. "In the last six weeks," said Mrs. Spare, "we've had two of them."

Bucks County started the de-institutionalization process earlier than the other counties, Mrs. Spare said, so has a more extensive experience from which to draw.

The released residents in Bucks County have had "multiple problems," she said.

"There's the lack of back-up services available in times of crisis," she said. "These people very often have crises. Coping with the change in lifestyle causes great problems. Many end up in mental hospitals because there's no other alternative. We're not able to send them back to Pennhurst for further rehabilitation and the providers (operators of the group homes) do not have the wherewithal to cope with the problems. So the people end up in mental institutions."

Although funding is supposed to be available for all the needs of the former residents, it is not, Mrs. Spare said. There often is not enough money for transportation, which means they do not get to their day programs, and not enough for medical and dental care.

"It can cost \$300 just for teeth cleaning because they must be anesthetized," said Mrs. Spare, whose 27-year-old daughter Sandra is a Pennhurst patient. And Medicaid only covers \$12 of the anesthesiologist's fee, normally hefty.

Plus, it is rare to find medical people able to cope with the severely retarded patient. In one case, Mrs. Spare said, the sister of a 30-year-old retarded woman was turned away from 12 hospitals in the Philadelphia area where she had taken the young woman after she had several severe seizures.

"And our girls are raped," Mrs. Spare said sadly. "They have illegitimate children. Babies born to retarded parents don't have a chance. Who wants to adopt a child if his mother is retarded? We can't sterilize them, we can't give them any instruction in birth control. We've had several incidents in the lower end of the county of them hanging around bars, into the drug scene. They're easily used. They want so much to have friends."

Cost increases

Mrs. Spare said it cost \$1.6 million last year to house and serve the retarded in community settings in Bucks County. It will cost more this year.

To disperse all of Pennhurst's residents throughout the five counties it will cost more money than the legislature has set aside for mental retardation in the entire state, she said.

"They do not have adequate time to do an adequate plan and we can't depend on the financial resources," she said. "The planners are theorists. This is reality."

Reality for Winnie Halderman is a tiny young woman who is barely toilet trained, who needs to be carried sometimes and who Winnie Halderman can't carry because of a bad back, a little girl at age 25 who likes to be loved and hugged.

That kind of reality has galvanized parents like Winnie Halderman and Polly Spare.

"Parents shouldn't be pressured into taking anything less than what they want," said Winnie Halderman. "I know I won't with Terri Lee."

Polly Spare is even more resolute.

"The last person to leave Pennhurst will be Sandra Spare," she said. "I'll turn the key in the lock."