

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."