

"I've seen what the voluntaries can do. I don't trust the state to take care of my son, and I think that's how most parents feel."

Crowell.

Advocates for the community clients understand the logic, but they are also furious over the shift in emphasis.

"You get people who say they've done the good thing, the moral thing, by keeping their child home and they're asking why they should be punished when those who abandon their child to institutions are rewarded," said Assemblywoman Elizabeth Connelly.

"There is absolutely no argument that de-institutionalization must continue," said Genevieve Benoit, chairwoman of the Staten Island Council for Developmental Disabilities. "But we want parity. That's the entire issue."

"We understand the pressure caused by the court order. We understand the time limit. But we think that two things can be accomplished at the same time. We can achieve parity and a system of services that leaves everybody better off. But we're not seeing it happen."

Some argue that the state should continue to let non-profit agencies operate group homes. That would maintain the 50-50 split, the argument goes, and the state would benefit because voluntaries can provide better ser-

vice at a lower cost. That was confirmed by a report published last summer by the New York State Commission on Quality of Care for the Mentally Disabled.

Yet the OMRDD is also under pressure by the employees' unions who want to avoid layoffs resulting from de-institutionalization and strongly encourage the state to have homes staffed by state employees.

"The state has some legitimate labor problems — de-institutionalization costs jobs, so the instinct is to go with state-operated homes," said Marjory Ames, director of the InterAgency Council on Developmental Disabilities in Manhattan.

Others are more bitter.

"It bothers me that the state is pushing voluntaries aside," said Mrs. Panzella. "I've seen what the voluntaries can do. I don't trust the state to take care of my son, and I think that's how most parents feel."

The realities of the situation have also inspired thought among some parents to place their retarded children in state care, if only temporarily, to ensure their priority in future distribution of services.

"Apparently, there is no law or legal precedent that entitles people to services automatically. There is no way to force the state to do anything for community clients," said Ms. Benoit. Yet, once a person is institutionalized, placed in a group home or put in

foster care, the state must assume some responsibility for that person's future.

"If you were a parent and aware that a mentally retarded child had no rights to service as an adult unless he or she was institutionalized in the system, what would you do?" said Ms. Ames. "We're not saying the state is forcing parents, but they sure are encouraging people to put mentally retarded children into state care to insure that they get services down the line."

"Many families like to keep their kids at home. But they know that if they do, it's with minimal help from the state. It's an awful thing to force on people."

State officials acknowledge the conflict, yet they say it is unavoidable. The state simply does not have the money or the ability to immediately institute a complete network of services for everybody.

"I understand what parents are saying, and we are sensitive to that. It's an awfully emotional issue," said Midge McGraw, spokeswoman for OMRDD. "I agree that more support services are needed for community clients, and I agree there is a need for more residential beds."

"I don't think advocates and parents want anything more than what state officials want. We are working toward the same ends. It's just a question of time."

(This is the third article in a six-part series.)

Page 2 of 2