

Parents of disabled told they must lobby

By JULIE MACK
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Parents of the mentally retarded and developmentally disabled were told last night to make their needs known and to "keep screaming" on issues they think are important.

"If you want group homes, you better start screaming now and hope to get them in five years," said Beatrice Victor, a longtime parent activist for programs for the disabled. "You must send letters. You must circulate petitions. You must contact the organizations.

"The time will come when you will need help. Don't wait for that moment. If you do, it will be too late."

Mrs. Victor was one of more than 30 parents at Chait Memorial Center, West Brighton, attending the annual open meeting of the Staten Island Regional Retardation and Disabilities Council (SIRDD).

The purpose of the evening meeting was to air parent concerns and encourage community involvement in the council, which is a consortium of local non-profit and government agencies and parent organizations that work with the disabled.

One issue which attracted discussion was the disposition of land at Staten Island Developmental Center (SIDC), which is scheduled to close by the end of 1987.

The state Office of Mental Retardation and Developmental Disabilities (OMRDD), which operates the center, plans to retain 90 acres of the 382-acre campus

and build four group homes and renovate old staff housing to create room for about 150 mentally retarded people.

The fate of the remaining 300 acres of land is currently under consideration by a task force of state officials and community representatives.

Genevieve Benoit, SIRDD chairwoman and a member of the task force, said at the meeting that proposals from the public on disposition of the land are now being accepted, and that people interested in giving their opinions should do so immediately.

She added that parents may wish to push the state to reserve more of the property for the mentally retarded, perhaps to be used for workshops, as a recreational site or to build more group homes.

"We don't have to settle for just 90 acres," she said. "We could ask for more."

"I have a big problem accepting just the 90 acres," Polly Panzella, a parent, said. "I think 290 wouldn't be enough."

One parent expressed skepticism that state officials would listen to community proposals. James Walsh, director of the developmental center and Staten Island's representative from OMRDD, acknowledged the concern, but said the only way parents have a chance of fulfilling their wishes is by making them known.

"We have to be careful not to be making trade-offs," Jane Milza, another parent, said. "We can't let our voice be divided — we can't have a case where some

people don't support one aspect of the plan because it doesn't help their child. We want it all."

On discussion of other issues, the parents were more quiet, sometimes to the frustration of professionals in the audience who said they were eager to hear from parents.

"You guys should be yelling at us," Walsh said. "You should be telling me what I'm not providing."

Linda Coulls, head of SIRDD's consumer group, also stressed the need to speak out. "You have to realize that when we are competing for dollars, we have trouble finding parents," she said.

"When we go to legislators, they always say they need numbers. They always say they want to see parents, as if they would believe it more if parents say it. There are a lot of dollars around, but there are a lot of people asking for it. The money goes to people who step in line first."