

# Doctor cites community watchdogs

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When the lid was blown off of Willowbrook 10 years ago, the defenders of the mentally retarded were vocal but few.

One of the major changes that came out of the revelations and the resulting consent decree was the creation of a large "constituency" whose goal is to protect the rights of the mentally re-

tarded, Dr. David J. Rothman, co-author of "The Willowbrook Wars," said yesterday.

"The absence of a constituency on behalf of the developmentally disabled had most profound effects," Dr. Rothman said, adding, however, that "one of the leading villains in the piece was the state Legislature."

In the early 1970s, Willowbrook and other institutions for

the retarded "were very, very far down on the appropriations list. . . . Recognizing to some degree that the absence of constituencies played a critical role, the state itself had not seen fit to do its job," he said.

It was the coming together of a number of events — a winning lawsuit in federal court, the state's belated allocation of funds for services and the new

involvement of community groups in caring for the mentally retarded — that has convinced Dr. Rothman that "it cannot go back to where it was.

"Not because I trust legislatures, and, in this day and age, with the post-Ronald Reagan changing of the federal courts, it's doubtful that the courts will be able to play the catalyst role that they once did."

But Dr. Rothman said he believes the groups who have become involved with the welfare of the mentally retarded will act as watchdogs over a state that will continue to cut as many corners as is politically expedient.

"I find myself far more comfortable and far more optimistic when I can find in a community a series of constituencies whose

stake it is to make certain that that which ought to happen does happen," he said yesterday at a forum titled "Caring for the Developmentally Disabled in the Jewish Community," held in the Manhattan offices of the Federation of Jewish Philanthropies, the sponsoring organization.

Dr. Rothman and his wife and co-author, Sheila Rothman, credited Jewish and non-Jewish community groups with keeping steady pressure on legislators to improve services for the mentally retarded and also for establishing many of the consent decree-mandated group homes.

The problem of neighborhood acceptance of group homes for the retarded has existed since group homes were conceived.

After the state "took a year fiddling around in the bureaucracy," while moving no closer the required housing of the retarded in small, community-based facilities, two parent activists turned to Jewish, Catholic and Protestant federations to underake the enormous job, Mrs. Rothman said.

"They said, 'We have 5,400 people we have to place. This many are Jewish, this many are Catholic and this many are Protestant. Can we begin to count on you?'" she said.

The groups responded positively, and were especially qualified to win acceptance for group homes in traditionally resistant neighborhoods.

"If it was a Catholic agency, and a father went before a Community Board and said, 'This is what we must do for our conscience, this is what God would want us to do,' you would get a very different response than if you brought in a group from outside," Mrs. Rothman said.

The very fact that group homes are located in residential areas also ensures a certain accountability, she said. "Neighbors watch. If the grass isn't cut, the neighbors will be angry. If you see people walking around without clothes, you don't want them on your block," she said. "That the staff knew people were watching became a very important part of the monitoring mechanism."

But, Mrs. Rothman's said, "What does it all mean, people often ask me, that the retarded were put into a community — that they weren't left institutionalized. Does it make any difference to people that are profoundly and severely retarded?"

She related the story of a group of blind and deaf retarded children who were moved from Willowbrook to a Manhattan group home.

On a sunny summer afternoon the staff took their new clients on a walk, but were suprised by a summer thunderstorm. "Before they knew it, the children had suddenly started to take off their clothes," she said. After getting the children dressed and back home, the staff "wondered why had this happened — what was the reason. They suddenly realized that the children thought they were in the shower — they had never before felt rain. So as you go on, please remember this story," she said.

Despite the progress in caring for the retarded since the consent decree was signed, though, society's response has not been perfect, nor are the current services ideal, the Rothmans said.

"The Legislature has been backing off its commitment," Dr. Rothman said, and the state Office of Mental Retardation and Developmental Disabilities "as opposed to group homes, would like to see large, 100-bed institutions."

Dr. Rothman once again turned to the importance of "constituency building" for the mentally retarded.

"The developmentally disabled are in a good position politically," he said, in large part because of "strange alliances" between "right-to-life people who are conservative in everything except Baby Doe-type issues" and a more liberal contingent that traditionally lobbies for the rights of the disabled.

"The traditional left and traditional right coming together on behalf of the disabled. The courts are no longer going to be an effective vehicle for reform. Always remember," he said, "you find your allies where you can."