

Willowbrook writers to talk on rights

The authors of "The Willowbrook Wars," on the controversy that resulted in the phase-out of the Staten Island Developmental Center, will be one of the featured speakers at a conference for Jewish parents of retarded children to be held April 29.

The conference "Caring for the Developmentally Disabled in the Jewish Community" will be from 9 a.m. to 3 p.m. in the headquarters of the United Jewish Appeal-Federation of Jewish Philanthropies in Manhattan.

The meeting is sponsored by the Joint Committee on Services to the Jewish Retarded of the Federation.

Dr. David J. Rothman and Sheila M. Rothman, who wrote the book on SIDC, formerly called the Willowbrook State School, in Willowbrook, will discuss the lessons to be learned from the fight for deinstitutionalization.

They will discuss alternatives that have surfaced since the center was closed to new clients and small, community-based group homes began to emerge.

Dr. Rothman teaches social medicine and history at the Columbia University College of Physicians and Surgeons. Mrs. Rothman is a Research Scholar at the Center for Social Sciences of Columbia University.

Other topics at the conference will be ethical considerations and the state budget.

Dr. Ruth Macklin, professor of bioethics at the Albert Einstein College of Medicine, will speak on ethics: The rights of patients versus the pressure to isolate them, the role of advocacy groups in bringing about change and who decides what is in the best interest of retarded people themselves.

Steven Sanders, state assemblyman from the 63rd A.D., Manhattan, will speak on the current state budget allocations and how they may affect services to the retarded.

In addition, four workshops led by teams of social service professionals and parents, will be given on the following subjects:

- How parents and professionals can work together to improve or create new services.

- The changed role and responsibilities of parents after their child has been placed in an institution.

- Alternatives of care for adult retarded children who age out of the child care system.

- Basic guidelines for elderly patients on how and when to turn over legal guardianship of adult retarded children.

"Parents face the same question again and again," Bella Nusbaum, chairman of the sponsoring committee, said. "What's the right thing to do? For each choice they make they must wrestle with complex ethical, legal and religious considerations."

Often, the biggest decision parents face is whether or not to place their child into an institution, she said. "No matter what the choice, the decision has a deep affect on the entire family."

Other problems confront parents. How do they make sure that proper care will continue when their child, at 21, no longer qualifies for the child service system?

The cost of the conference is \$10 a person, and includes all materials and a kosher lunch. Pre-registration is required. Parents who wish to attend may call the Federation at (212) 980-1000.