

Seven years have passed since disclosure of the atrocities at the Willowbrook Developmental Center on Staten Island forced New York State to abandon its policy of confining the mentally retarded to large institutions. A United States District Court decree mandated return of residents to home counties to be cared for in small-group homes, individual apartments and foster and natural families. Although the state has met community resistance in implementing this decree, it has also been impeded by its own confused priorities. A prime example is its circumvention of a recent State Supreme Court decision, in *Sundheimer v. Kolb*, that provided financial assistance for natural parents caring for their retarded children at home. As a result of the state's action, Willowbrook parents are soon to return to Federal court to urge, once again, compliance with the decree.

Today, only 3 percent, or 15,000, of New York's 500,000 retarded citizens reside in state institutions. Nevertheless, most of the state's money for residential care is still poured into these obsolescent establishments. Only 10 percent to 20 percent of the budget is left for the much-larger number of retarded persons who require assistance to live in the community.

Community care is more humane than institutional care and the cost to the state for total care, including room, board and adequate support services, is far less. Family care is most economical since the parent already has a household. State assistance in cash or direct services totaling roughly \$10,000 a year is sufficient to enable parents of modest means to take care of a retarded child at home. Apartment-living programs and community group residences are fine alternatives when properly supervised. They cost more than family care but less than the \$25,000 to \$45,000 spent annually per person in large state institutions.

Considering the large number of re-

## Willowbrook Victims

By Harry H. Gordon



tarded persons in the community needing care, and limited state resources, family-care assistance should have a top priority. Unfortunately, it does not, as demonstrated by the aftermath of *Sundheimer v. Kolb*. At issue in the case was the state's family-care program for retarded persons, which certifies families to serve as foster parents. In addition to standard state and Federal welfare grants that foster

parents get, the state reimburses them for food, clothing and other basic necessities for the children.

Not all families, however, were considered eligible for this aid. Under Department of Mental Hygiene regulations, natural parents who had placed their children in a state institution for more than two years, and foster parents, were eligible; natural parents who had never institutionalized their

children were arbitrarily declared ineligible. Outraged, they went to court. The state, they charged, offered a bounty to parents who had institutionalized their children while denying similar assistance to parents who, at considerable emotional and material cost, had provided home care for equally disabled children. The court agreed, ruling that *all* natural parents providing home care were eligible.

Unbelievably, the State Office of Mental Retardation, created to help retarded children and their parents, undermined the decision. Instead of following the court's order, the then Commissioner of Mental Retardation, Thomas Coughlin 3d, closed the family-care program to all natural parents regardless of the severity of their child's retardation or prior institutionalization. Thus, administrative fiat evaded the judge's directive. Under Mr. Coughlin's order, all natural parents are now equally *ineligible* to receive family-care support. As a result, natural parents who are willing to care for their children at home are denied help no matter how handicapped the child and how poor the family.

The Willowbrook decree to stop warehousing the retarded prescribes an equal moral obligation to minimize the need for parents to send their children to distant institutions. The termination of family-care funds for natural parents circumvents the aims of the decree.

If the state is to provide humane care in the community — a matter of equity and sound economics — the commissioner and the Legislature should first correct the funding imbalance between institutional and community care. Second, since the state's resources are limited, funds for community care should be allocated on a basis that gives priority to parents of low and middle income.

Sadly, this was not the attitude of the state courts in a recent case where the court permitted a wealthy parent to dump his obligations for a retarded child over 21 on the state. Ignoring the divorced father's wealth, the court refused to reach a just result, determining that he had no responsibility to support his daughter. Thus, the state and Federal Governments must support her with welfare grants earmarked for the poor and handicapped.

The Willowbrook decree will become a blessing only when the state moves toward humane care for all mentally retarded persons according to their needs, whether they reside with their families, in group homes, in apartments, or for the time being in large institutions. This would constitute a true implementation of the letter and spirit of the decree.

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