

# Another View of Willowbrook

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By JACK HAMMOND

In their efforts to stir the conscience of society and to call attention to the need to improve the care of the institutionalized retarded and to expand community-based programs, the media have rendered a great public service.

However, one must bear in mind that Willowbrook State School, which has been the focus of the recent publicity concerning the mentally retarded,

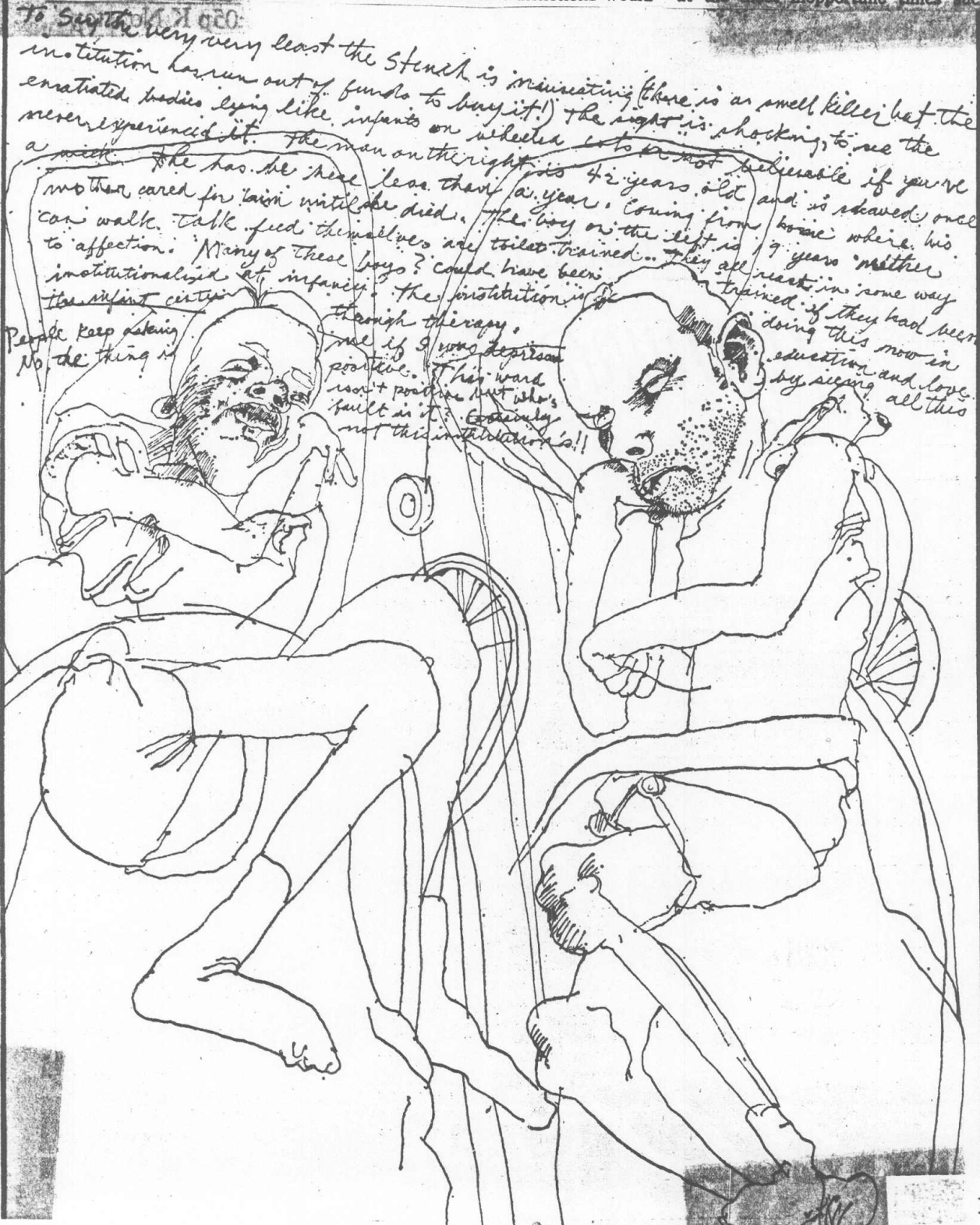
serves a very severely and profoundly handicapped population. Seventy-seven per cent of our patients are severely or profoundly mentally retarded; 39.1 per cent are nonambulatory with severe spasticity due to cerebral palsy or other neurological conditions; 30 per cent have histories of convulsive seizures; 52.8 per cent have no speech; 60 per cent are incapable of adequately attending to their own personal hygiene; many are hyperactive or disturbed.

The sight of one individual with a combination of such afflictions would

cause great distress and anguish to anyone with any compassion at all. The sight of large numbers of such individuals gathered in one location such as Willowbrook is even more distressing.

The reader or viewer should realize that with 5,000 patients at Willowbrook, of whom about 4,000 are as described above, there are numerous buildings housing these individuals which replicate themselves.

Some of the media repeatedly zeroed in on this target population, frequently at the most inopportune times such



...when the residents were being showered and were therefore naked as they entered and left the bathing areas; or immediately after meal time when unavoidable food spillage had not yet been cleaned up and patients were being toileted, presenting a distorted picture.

The media have never been barred from Willowbrook State School. When media representatives did visit they were always shown a balanced picture which included a number of our problem areas. In turn, the media previously always presented a balanced picture to the public. However, during the recent publicity many of the media representatives absolutely refused to see anything but the most unpleasant situations.

It was not necessary for media representatives accompanied by scores of irate parents and indignant officials to barge in through the back doors of buildings, climb over residents and disrupt employes in the performance of their duties in order to obtain factual information about conditions in the institution. It has never been the policy of this administration to forewarn the employes of impending visits by the press or by officials and whether they arrived announced or unannounced such visitors have always been promptly escorted to all parts of the institution, with no special preparations made for their visits.

The comparisons which have been made between the retarded in the various community centers in New York State and elsewhere and the profoundly retarded multiply handicapped whom we have at Willowbrook State School have also been distorted. Almost all of the Willowbrook population in this category would be found "not suitable" for enrollment in those community programs.

With rare exception, little or nothing has been shown on television or described in the newspapers concerning the many programs for the training and education of our somewhat more capable patients and the better living conditions that naturally follow for those patients who have self-help skills and who can feed, bathe and dress themselves. Nothing was shown of our fine school department or infant therapy complex or the work of the physical therapy, occupational therapy or recreation departments. No mention was made of our several unique programs for the habilitation of younger patients and the preparation of our young adult patients for community living. Our volunteer program, the largest in any of our institutions, involving several thousand volunteers, understaffed and overworked, has been maligned.

We at Willowbrook have for years been in the forefront of the fight to improve the living conditions, the staffing and the programming for our most helpless residents. The unpleasant conditions, serious overcrowding, shortage of help and absence of viable programs in so many areas of Willowbrook State School have repeatedly been reported to the proper officials and to the parents' organization. To

...more money was made available during the past few years, there has been improvement in these areas, but not enough.

A great disservice has been done to the many sincere, dedicated, hard-working employes of this institution who labor under the most trying circumstances. No recognition has been given to their herculean efforts. Instead they have been criticized, shamed and even abused. Their morale has been devastated.

The anxieties of many parents who had placed their profoundly retarded, often multiply handicapped, offspring in a residential setting as the only alternative to disruption and decompensation of the rest of the family, have been aroused. They are now beset with doubt and feelings of guilt.

Somehow the public seems to have gained the impression that New York State provides no services for the mentally retarded other than that which is available in our residential facilities. Somehow the fact that only approximately 2 per cent of the mentally retarded reside in our institutions and that 98 per cent of them reside in the community, mostly with their own families, seems to have been over-

Drawing: Alan E. Coker

looked. Over 50,000 mentally retarded youngsters between the ages of 7 and 21 years are enrolled in special classes in the public schools throughout the state. More than 26,000 mentally retarded youngsters and adults who are either too young, too old or otherwise ineligible for the public school classes are being helped to remain in the community by 200 community-based programs, representing a total state and local expenditure of \$14,000,000.

Let us beware of false prophets. While absolutely agreeing that more community-based programs are essential, we must bear in mind that there will always be some for whom there will be no alternative but a residential placement unless society chooses to return to the ancient practice of abandoning its helpless members on the mountainside.

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