

# Willowbrook Budget Cut Also Hurts the Parents

By LISA HAMMEL

After the red-haired toddler had gone through the crayons, gleefully demolished the paper, and then stolen a potato chip, she trudged over to the coffee table where she spotted a Plexiglas cube lined with snapshots.

"Me," she said, in a pleased voice, pointing to a snapshot of herself and another pretty little girl. "Lara," she said, pointing to the other child—her older sister.

But although active and voluble Elizabeth is only 1½ and her sister is two years older, Lara can't do any of the things the toddler had been doing.

For the older sister is mentally retarded.

Lara, the first child of Mr. and Mrs. Murray B. Schneps, has spent more than two-thirds of her young life in an institution, locked into what may be perpetual infancy because of brain damage apparently suffered during her birth.

She had begun to respond a little to the therapy and the love and care she was being given at Willowbrook State School for the mentally retarded. But now her parents are haunted by the "nightmare" that even the care she was receiving will be crucially diminished as a result of cuts made by the Legislature last spring in the state mental health budget—with more cuts proposed for this year.

## Living With Anguish

"It takes 35 minutes to feed Lara," said Mrs. Schneps the other day, as she sat in the living room of their Bay-side, Queens, high-rise. "There are 50 children in Lara's ward, and 35 of them have to be hand-fed. All 50 need to be diapered and dressed. I can't say enough for the attendants. I know that Lara is loved and cared about. But there are only two attendants now to do all this. How can the children be adequately cared for?"

Mrs. Schneps spoke matter-of-factly. Anguish is something she and her husband have learned to live with. They have had more than three years of practice.

And in any case, Murray and Vicki Schneps are not people who take things lying down. Mr. Schneps, as a lawyer, has tried to prevent the closing—as the result of the budget cut—of two state schools for the retarded (he was successful with only one), and is on the board of two organizations concerned with the retarded.

And 10 months ago, Mrs. Schneps formed her own organization, of which she is president, to help the retarded children at Willowbrook—a 400-acre institution on Staten Island whose 5,100 patients range from infants to octogenarians.

## Letter Campaign

Mrs. Schneps is the only member of the Women's Organization for Retarded Children (its acronym is WORC) with a retarded child. "I thought there were a lot of people who would want to help," she said, recalling how the organization was formed, "if they knew about the problems."

Apparently she was right, because she has managed to rally 150 members ("we may have to change the name soon because we're getting a lot of men involved") from four of the five boroughs, as well as Nassau County.

Their first act as an organization was to mobilize friends, neighbors, relatives and co-workers in a letter-writing campaign ("we literally got thousands of letters sent," she recalled) to the Governor and Legislature to head off the proposed budget cuts last spring.

Since then, the members have been devoting themselves to fund-raising events, as well as care of the children at Willowbrook. Each member agrees to become a "mother" to one or more young patients, and visits her charge regularly at the state school. According to Mrs. Schneps's estimate, 80 per cent of the children at Willowbrook have been abandoned by their families.

The next big push, said Mrs. Schneps, will be to consider a mass visit to Albany to talk individually with legislators, in an attempt to reverse the budget cuts.

While the patient population remained almost stable in 1971, the staff, largely because of the budget cuts, has been reduced from 3,628 to 2,716.

The National Accreditation Council for Facilities for the Mentally Retarded recommends a patient-to-attendant ratio of 4 to 1. Willowbrook's ratio ranges from 20-to-1 to 30-to-1.

Last month a delegation of state legislators began to investigate the situation at the state school. And yesterday a full-scale investigation was called for by State Assemblyman Andrew Stein when it was learned that a Willowbrook doctor and a social worker had been fired for discussing problems at the institution with a group of parents.

For Mrs. Schneps, the awareness of the great needs of thousands of retarded children came only after she had ceased being totally benumbed by her own.

The Schnepses had waited five years to have a child, while they developed their respective careers, so Lara's birth was an event of great joy.

But when month after month passed and the child never moved, nor cried, nor responded to all the loving attentions her parents provided, and her condition was finally diagnosed as severe and possibly irreversible brain damage, the joy turned to anguish—and then guilt, at the thought of putting her somewhere.

At first, Mrs. Schneps recalled, "we both fell apart." But then at the suggestion of two cousins who were social workers, the couple went into psychiatric "crisis therapy."

After giving up the idea of a private institution, because the only ones that were willing to accept "a child without potential" were "above-ground cemeteries," they investigated Willowbrook, where there is a new and extensive infant rehabilitation program.

They were finally convinced to send Lara to Willowbrook when it was pointed out to them that the only hope for the child lay in rehabilitative therapy —

begun as early as possible.

While there are parents' associations at most of these state schools (the Schnepses are active in the one at Willowbrook), Mrs. Schneps said that many outside hands are needed to help.

Her aim is to enlarge the membership and scope of her own organization, as well, she hopes, as serving as a prototype for other outside organizations that might be formed to help the retarded at other state schools.

"I can't believe," she said, stopping now and again to hug Elizabeth or keep her from cravoning all over the velvety pink rug, "that if people knew that children were starving because there weren't enough hands to feed them, that they wouldn't want to help."