

# Why Queens Father Took Child Out of Willowbrook

By JOYCE PURNICK

Lara Schneps isn't at Willowbrook State anymore.

She probably won't be back.

Pretty, red-haired Lara is home, lying quietly in her mother's arms, as her parents talk about their decision to take Lara out of the state-run institution for the mentally retarded.

"You make a bargain with God. You say, please God, let her live, let her be healthy. You tell yourself you're doing the best possible thing. But deep inside, you know you're kidding yourself. And you have to face the fact that your child is living in a death hole."

Sitting with his family in their Bayside, Queens, apartment one recent afternoon, Murray Schneps' controlled voice breaks in anger as he talks about the place where his daughter has spent most of her 3½ years.

"You know when I started to realize that place was not for my child? One day I went with parents and the press on a tour of a building right next to Lara's. It was a horror. And I realized—it's the same as Lara's ward. But when I'd visited my daughter's ward, I went in with

blindners."

Schneps and his wife, Vicki,—both long active in the fight against deteriorating conditions at Willowbrook—say the blinders came off permanently last Monday afternoon, when they found only one attendant on duty to care for the 45 to 50 helpless children on Lara's ward.

Ordinarily, there are two—still far short of the federal standards that call for a ratio of one attendant for every four patients.

After calling on the administration to bring in additional staff, and alerting TV news stations in the hope that publicity would focus attention on the plight of Willowbrook, the Schneps wrapped Lara in a blanket and drove her home.

Lara, with deep blue eyes that cannot see, legs that cannot support her frail body, arms that can't hold a toy or grasp a bottle, is profoundly and severely retarded.

Doctors say she will never be able to feed herself, control her bodily functions, learn to speak, or even hold her head up.

Because she is helpless, and has a tendency towards seizures — controlled with daily doses of Valium and

Phenobarbital — Lara requires constant observation.

The Schneps first placed Lara in Willowbrook when she was 14 months old, after doctors convinced them that chances for her mental development were all but impossible.

They chose Willowbrook because it then had the reputation of being one of the best institutions in the state. "When we first placed Lara, we thought she was in paradise. They had a very impressive infant care therapy program. Willowbrook appeared to be the best available."

That was back in 1969, before the recent budget and staff cutbacks that have brought Willowbrook and other mental facilities in the state into the headlines.

Lara's parents say that taking her out of Willowbrook and caring for her at home is no permanent solution.

Because Lara requires daily physical therapy to prevent her limbs from stiffening permanently, because she should be near the best medical facilities, because she needs constant observation—for any number of reasons, Lara should be in a residential facility.

Convinced that a residential program is best for them and for their daughter, the Schneps have been looking out of the state—even out of the country—for an appropriate facility. They don't want to consider returning Lara to Willowbrook.

Both continue to fight for Willowbrook. Mrs. Schneps is founder and still president of the Women's Organization for Retarded Children (WORC) and her husband, active in several parents' organizations, testified yesterday at an HEW hearing into Willowbrook. "I will never let my mind veer from Willowbrook," Schneps says. "I don't want to consider dropping the cause."

"You have to face the fact that your child is living in a death hole," says Murray Schneps of Bayside, who decided to take his mentally retarded daughter, Lara (in his arms), out of Willowbrook State. With him are his wife, Vicki, and another daughter, Elizabeth. Story on page 54.