

Retarded child at home

What can parents do?

By JANE KURTIN

As the horrors of Willowbrook State School unfolded over the past few months, parents of normal, healthy children, asked repeatedly: "How can anyone put their child in a place like that?"

Those who followed the chronicle of suffering at Willowbrook and chose to pass judgment, invariably judged first against the institution and second against the parents who they felt, had failed their responsibilities.

Through all this, the parents who struggled through the grueling daily routine of living with, caring for and training a retarded child, had nothing but sympathy for those who found Willowbrook as their only alternative.

Interviews with five mothers, who requested that their names be withheld, offer an insight into the devastating effect of having one helpless and often destructive family member in the home.

The simple pleasures, like going to a movie or to dinner with the family are, according to these parents, out of the question.

Shopping, whether it's just for the week's groceries or for Christmas presents, represents a major outing to be planned well in advance and involves the cooperation of many people. And, for each of these women,

the fear of becoming ill themselves is a constant burden. If one of them requires hospitalization, for instance, there are amazingly few friends or relatives that can come in and handle a retarded child.

For those who do keep their children at home, there is the constant self-questioning and guilty conscience over the effect on the family that keeping the child has.

In most cases, mothers are constantly forced to ask themselves if it's worth depriving the normal children of attention, if it's worth forfeiting normal lives for themselves, if it's worth the financial stranglehold to house a person who will never, ever, be on his own.

Generally, it is not heroic mothers and fathers who vote against institutions like Willowbrook, but parents who have decided simply that one kind of guilt is less difficult to bear than the other.

Better to hope that the strains imposed on the healthy members of the family will not have to devastating an effect, than to know that a retarded son or daughter is doomed to a loveless, empty life in the stench of Willowbrook.

And, as if their own doubts were not enough to torment them, parents of the retarded are destined to withstand the suggestions of well meaning relatives and friends.

Constantly, the refrain "put him away, you owe it to your family and yourself" gnaws at the foundation of parents' tenuous conviction that what they have chosen to do, is all they could have chosen.

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