



Leovarda Ruiz with her daughter, Maria, at apartment managed by United Cerebral Palsy on Upper West Side.

About New York

A Child Comes Home From Willowbrook

By ANNA QUINDLEN

About 24 years ago, just a few months after her first birthday, a little girl with tight brown curls named Maria Ruiz became the responsibility of the State of New York.

She went to live in a big brick building in the complex on Staten Island then called Willowbrook, and every Sunday her mother and father took a bus, a ferry and two more buses on the other side of the bay to visit her in a drab little waiting room. She was profoundly retarded, and rigid and ungainly from cerebral palsy, but she smiled a lot.

Her parents never visited the ward in which she lived and slept. Her mother, Leovarda, who had the same curly hair, sometimes had nightmares about her daughter, but she could not say exactly what they were or what they meant.

This month, after spending almost her entire life in institutions, Maria will be put into a van in her wheelchair and driven to her parents' home in the Bronx to live with Wilfredo and Leovarda Ruiz, who bore her but did not know what to do with her when she was a baby and they were young.

Maria has not changed very much since her parents decided to institutionalize her so many years ago, but the world in which she has not lived has changed a great deal. There was a great outcry about Willowbrook in particular and institutions in general; there were doctors who decided that retarded children would grow best with their parents, and parents who decided that, too.

And there is Maria, who is going home because of all those things, and because, at base, her parents never really stopped feeling that they had done something terribly wrong when they listened to the doctors and sent their firstborn away.

"We always think about this because we do not want to put her in," said Mrs. Ruiz, sitting knees to knees with her rag doll of a daughter and running her hands up and down the short calves in their pink knee socks. "I went to the doctor when she was four months, and I asked the doctor why she put her head to the back like that and why she does not have the movement of a child that age. The doctor told me she was lazy.

"But then, at seven months we take her to St. Vincent's, and then they find out that she is brain-damaged. The doctor told me that the best thing was to send her to Willowbrook. We don't want to send her over there, but then I get pregnant with my son and I can't have two children like that." And she folded her arms' like a mother holding an infant.

Mrs. Ruiz's son grew up to become an electrical engineer, and her daughter grew up to be a baby, for while Maria's body has traveled through adolescence into adulthood, she wears the clothes of a small child — pink dress with lace collar, black Mary Janes, socks, diapers — and her mind has remained just about where it was when her parents took her to the doctors at St. Vincent's. She recognizes her mother, and she bounces up and down in her wheelchair when music is on the stereo, but she cannot walk or wash herself. She has learned one word in her life: "Papa."

Maria might have lived and died in an institution if the parents of some Willowbrook patients had not brought a class-action suit charging that the facility was overcrowded and inadequately staffed. In 1975, a Federal judge gave the state six years to change conditions, and one of the changes was Maria. She was

moved into something called a Post Institutional Placement Program run by United Cerebral Palsy of New York State.

For the last year, in response to the judicial decision that mandated life for her and others like her "in the community at large," she has lived in an apartment managed by the organization in a big old prewar building on the Upper West Side, going every day to a school where she is trained to groom and feed herself. On the bureau in her bedroom there is a baby picture: bright eyes, sturdy little shoulders, a dark spit curl rising above the low forehead, a Gerber baby of a little girl.

Mrs. Ruiz put it there. She is always with her daughter now that it is possible, now that her guilt has been tempered by time and change. Mrs. Ruiz sometimes takes Maria home for the weekends. The neighbors in the Ruizes' Bronx apartment building hover around as though Leovarda was bringing a new baby home from the hospital. Maria twists her head and smiles.

"You have to wonder," said Toby Kleinhandler, who once worked at Willowbrook and is now associate director of the Post Institutional Placement Program, "what would have happened if she had had this kind of life early on."

Since Maria has been living in the

apartment, she has had many small victories. She makes eye contact with strangers, can feed herself with a special spoon and bowl and accepts hugs and praise as rewards now, rather than food. Her parents decided that they wanted to take her home. They were interviewed and questioned and assessed and evaluated.

Willowbrook was once the "providing agency" for Maria's care. Now her parents become the providers, although primary responsibility for their daughter will stay with the state, which can provide services and care Mr. and Mrs. Ruiz cannot. The parents are not opposed to entering into such a partnership; they are working people in their early 50's, and while their daughter is an infant in so many ways, her body is strong and she may outlive them.

"Now I can sleep very well with her in my house," Mrs. Ruiz said. "Because sometimes before, I go to bed and I picture things. Too many things have happened."

"I need only some other person to take her from the bath to here," she said, laying one hand on the padded arm of the wheelchair. Then she blew her daughter a noisy kiss. Maria raised her head from her chest with some difficulty and smiled the smile of the perfectly innocent.