

TRUE LIFE STORIES

A HOME OF THEIR OWN

This year, Christmas Eve at 48 AB Executive Way will be much the same as Christmas Eve anywhere else. A pile of gifts tied with colored ribbons and bows will be placed beneath a seven-foot tree trimmed with powder-blue doves, twinkling lights and yards of silver garland. Stockings will be hung above a brick fireplace in the living room, and upstairs, household members will rest fitfully, awaiting the moment when they can rush down and tear the wrapping from their holiday prizes.

But this is no ordinary household. The six women who live here are all mentally retarded. And four of them once lived in the Willowbrook State School, an institution for the retarded in Staten Island, New York, that was known as "America's concentration camp."

Jean,* now 47, came to Willowbrook in 1955. Her mother had died, and as is the case with many of Willowbrook's residents, her

Once considered ineducable, five happy women make preparations for holiday fun with the help of manager Marie Ortiz (second from right).

The nightmare of Willowbrook is over. Today these mentally retarded adults live in homes filled with love
by Joseph L. McCarthy

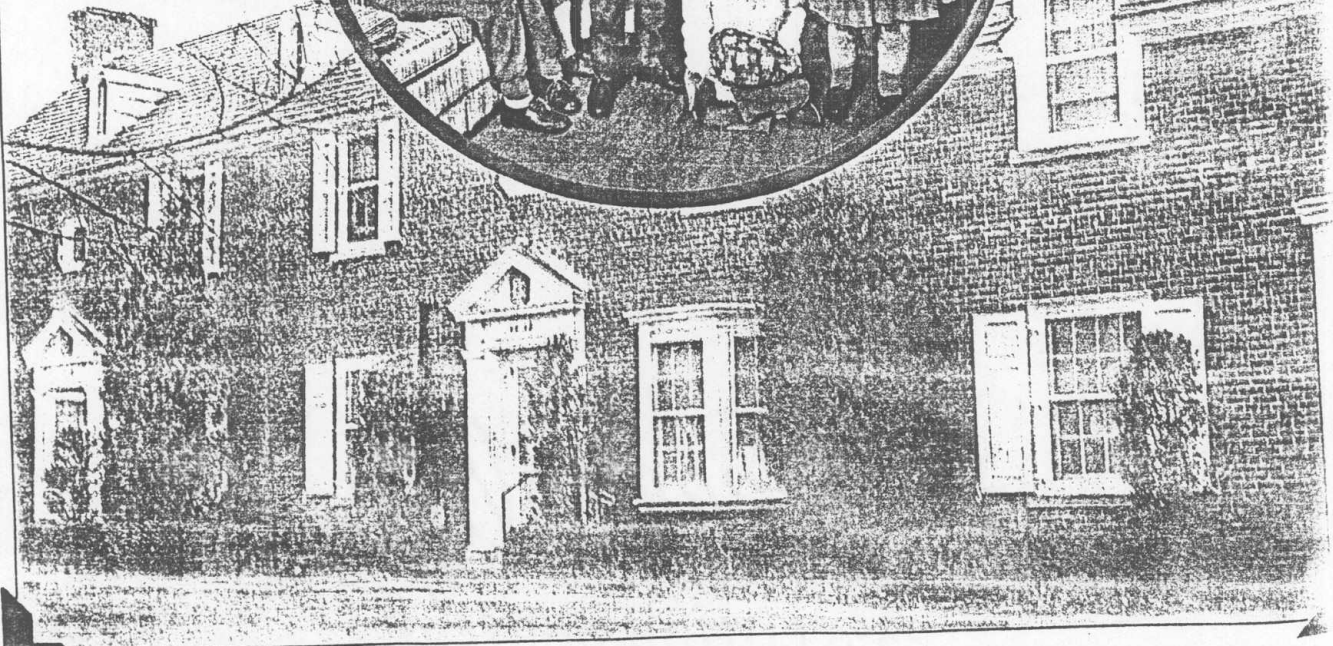
surviving family was no longer able to care for her. Often, in anger, she would attack those around her or violently smash her head against the wall. After several years at the school, she was moved to building number two, where heavy sedation, straitjackets and solitary confinement were commonplace.

Mary entered Willowbrook in 1960 at the age of seven. She was diagnosed as severely retarded, hyperactive and epileptic. One day, after ripping an attendant's uniform, she was transferred to a ward that housed 60 other highly disturbed, violent patients. "My little girl came out of that building blind in one eye, with a broken nose and scars all over her body," says Mary's mother.

Jean and Mary still live at Willowbrook, but now that once-dreaded name stands only for a
(please turn to page 68)



PHOTOGRAPHS BY MYRON MILLER



*The names of the residents have been changed.

A HOME OF THEIR OWN

continued from page 66

quiet Staten Island neighborhood—not for the human warehouse that used to be there. In 1986 New York State closed the institution and opened 12 residential apartments for the mentally retarded on the outskirts of its former 382-acre site; 48 AB Executive Way is one of them. The women who moved there, however, have more than new addresses. They have new lives.

Nowadays Jean and her friends go dancing, attend special schools in their community and enjoy boat trips and hayrides in the country. With help from the staffers who work at their home, they clean house and shop for their own clothing and groceries.

All told, 11 staffers work at 48 AB Executive Way in three shifts, along with a recreation therapist, social worker, dietitian, psychologist, nurse and speech therapist, who are also responsible for other residences.

"The minute these women came here, they began to get better. Their turnaround has been almost miraculous," says Marie Ortiz, a former Willowbrook employee who is now the apartment's manager and a part-time surrogate mother to the women who live there. "In Willowbrook they were treated like animals. Now they're a family."

Not everyone in the family came from Willowbrook. Susan, at 27 the family's junior member, came to Executive Way from her mother's Staten Island apartment. And not all of the women were born mentally retarded. At age four, Rose came down with scarlet fever, then contracted encephalitis, an inflammation of the brain that left her with a progressive form of mental retardation.

This Christmas season the women will travel to see the giant tree at Rockefeller Center—a shimmering emblem of the New York holiday season. They'll dine by candlelight on roast turkey, cranberry sauce and hot biscuits. And they'll attend their annual Christmas disco/pageant, where they'll sit on Santa Claus's lap and ask him for gifts.

But this Christmas, along with the packages they'll receive from Santa, their families and the apartment's staff, there will be other gifts. Jean and Mary seldom lash out anymore. Sixty-nine-year-old Marcia, who had been ripping out her hair by the handful when she moved into her new home, has grown back a gorgeous head of snow-white hair. Sally, age 40, who used to be "hell on wheels," according to a former staffer at the institution, now does her wheeling around on the dance floor. And the greatest gift of all just might be the apartment itself—and the kinship it has engendered.

"They found each other," says Ortiz, "and that has made all the difference."

Willowbrook had been conceived amid great expectations: It was to be the first state institution for the mentally retarded to admit children under five years of age. But almost immediately after Willowbrook opened in 1947, its population began to soar. By 1956 the institution, built to accommodate about 3,100 residents, held 3,900. By 1962, after an expansion program that increased Willowbrook's capacity by 1,200 beds, the school's population had swelled to 6,200. Under such conditions, individual attention was virtually impossible, says Katy Tucker, a staffer at 48 AB Executive Way who started working at Willowbrook in 1958. Resident-staff ratios often exceeded 100 to 1. Children were herded to meals "in packs, like cattle," she recalls, and they often went weeks without a shower or change of clothes. Because of the filth and overcrowding, intestinal diseases, such as shigella, swept through the population. In May of 1965 a ten-year-old boy was scalded to death in a shower, partly because of the school's archaic plumbing. A month later a 12-year-old suffocated to death when a restraining apparatus loosened and became wound around his neck.

Such was the Willowbrook that Jean found upon her admission there. Responding to the squalor and neglect, she lost an eye through self-abuse, staffers acknowledge.

In 1972, amid steadily deteriorating conditions, Mary's mother and scores of other Willowbrook parents finally revolted. Aided by the American Civil Liberties Union, they filed suit against New York State. At about the same time, more than a dozen other states—including Illinois, Pennsylvania and Texas—became involved in similar litigation. As these cases were settled, plans were laid to close or trim many institutions and to place their residents in community-based group foster homes. In the early 1970s there were no more than a handful of group homes; now group homes serve an estimated 114,000 clients. Some homes, like those on Executive Way, have been built on the grounds of dismantled institutions, but most are in regular communities. Because of the group-home movement, the institutional count of retarded people fell from 194,650 in 1967 to 94,696 in 1987. According to the most recent survey by the Association for Retarded Citizens of the United States, at least 64,000 people are on waiting lists to enter community-based facilities. And what began as an experiment in social services has emerged as a dramatic success.

It's daybreak at Willowbrook. In the eerie half-light, one can see that the windows of the empty, low-slung ward



buildings are sealed shut with heavy sheets of plywood or tin. Marie Ortiz used to work in one of those buildings. But today she drives past the abandoned complex and parks in front of a two-story, brick garden apartment, its front neatly appointed with evergreen hedges.

Inside, the dwelling radiates an easy charm. In the dining room, two rock-maple dining tables are set with cornflower-blue tablecloths and magenta silk flowers. The living room is furnished with a couch, a pair of soft easy chairs, an exercise bicycle and a 25-inch console color television. Scattered about is an assortment of toys and games: building blocks, a checkerboard, a jigsaw puzzle and a fuzzy white unicorn with a pink horn.

Jean pads downstairs and bids everyone a cheery good morning. Assisted by Charlotte Young, the house's director, Jean sits and softly hums a tune. "She knows the melody to 50 or 60 songs by heart," says Jean's sister-in-law. Jean never sang at Willowbrook.

Other family members filter down to the breakfast table. "Who's going to say grace?" Young asks. "Me!" Jean volunteers. The family digs into a breakfast of scrambled eggs, hot cereal, toast and coffee.

When she finishes her coffee, Mary bangs the table with her fist, points to her cup and shouts at staffer Katy Tucker, who prepares their meals, "Want!"

"I want," Tucker reminds her charge.

"I want," Mary replies.

"You want what?"

"Coffee."

"You want coffee, what?" Tucker coaxes.

"Coffee, please," Mary finally responds. With a heartfelt laugh, she bounds from her chair and wraps Tucker in a steel-trap bear hug.

The severely and profoundly retarded, whose I.Q.'s are less than 40, were once thought to be uncontrollable and ineducable. "Many of them may never learn to read or write," says Dr. Mary Howell, assistant clinical professor in pediatrics and geriatrics at Harvard Medical School and a Joseph P. Kennedy,

Jr., Scholar in Geriatrics and Mental Retardation. "But through consistency and repetition they can be taught to feed, dress and groom themselves and to clean house—activities that increase their independence and self-esteem."

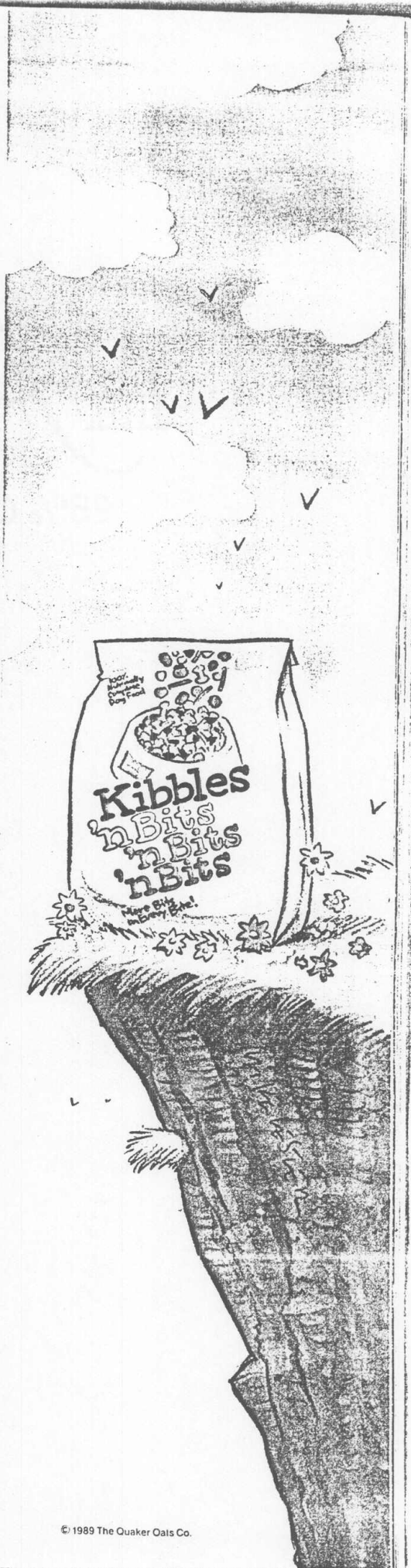
For the more mildly retarded, Dr. Howell says, mastery over such tasks might facilitate their admission into a job-training program, or even a move to an apartment of their own. But for Jean and her housemates, learning these skills might simply mean "graduating" to a group home with a more independent environment. Because of the shortage of group homes and the painstaking process of teaching the retarded necessary skills, moves are relatively infrequent, says Harris Rimshnick, who administers several Executive Way units.

Still, when moves are proposed, they're often cause for celebration. "One of our residents was moved to a less restrictive house last week," Rimshnick says. "It was practically next door, but he couldn't stop bragging to his housemates: 'I'm going up the road.'"

Breakfast is finished. Marcia totes her dishes to the kitchen; Sally grabs a dustpan and begins to sweep the dining room floor. Rose, assigned to report to the family on the day's weather forecast, has become enraptured by Jane Pauley on the *Today* show. Jean trundles out the door to take the bus to a special-education program in a nearby neighborhood. Seeing her out, Ortiz smiles.

"Her brother never thought she'd make it in a group home," Ortiz says. "It's really incredible, isn't it?"

Almost as incredible is that the idea of group homes for the mentally retarded caught on at all. At first, even many who were appalled at institutional conditions opposed them. "In effect, group homes second-guessed a parent's decision" to put away a family member, points out attorney Chris Hansen, who helped to press the Willowbrook case against New York State and is now associate director of the American Civil Liberties Union's Children's Rights



Moving?
Let us know
eight weeks
before you go.

For fastest service, attach your current address label (from magazine cover) in the space above. Then fill in your new address and

mail to: McCall's/P.O. Box 56093/Boulder, CO 80322-6093 1 yr. \$13.97

12-89

Attach your address label from current issue here.

NEW ADDRESS:

Name

Address

City, State

Zip

A HOME OF THEIR OWN

continued

Project. "After all, if they could live in homes, the question became, Why didn't the family keep them in the first place?"

Perhaps the most formidable obstacle to group homes, though, has been resistance from the neighborhoods and townships in which they've been located. According to Ellen Ashton of the New York State Office of Mental Retardation/Developmental Disabilities, four facilities in the New York area were set on fire when they were under construction or renovation: in Queens in 1987, in Northport in 1981, in Shirley/Mastic in 1980 and in Huntington in 1978. In 1985 neighbors in Russell Gardens, a Long Island community, tried less violent tactics: They chipped in and bought a house to keep it from becoming a group home.

Elsewhere, municipalities have passed laws designed to exclude the mentally handicapped. In 1980, citing a regulation barring "hospitals for the feeble-minded," the city council of Cleburne, Texas, denied a zoning permit for a group home. In 1985 the U.S. Supreme Court unanimously agreed that the permit was unconstitutionally denied; subsequently, 13 retarded men and women moved into the house.

A flyer taped to the wall of a down-

stairs bathroom at 48 AB Executive Way reads BEING MENTALLY RETARDED NEVER PREVENTED ANYONE FROM BEING A GOOD NEIGHBOR. But given the terror that group homes have generated, how many neighborhoods really have given the mentally retarded that chance?

The Russell Gardens episode ended on a happy note. On appeal, a New York State Supreme Court justice ruled that the residents' purchase of the prospective group home was illegal. The state eventually purchased the house, and 12 mentally retarded men and women moved in. The new arrivals then threw a coming-out party for their neighbors, serving them bagels and cream cheese, cakes, cookies and hot coffee.

Staten Island also has had its share of success stories. "One group home in my neighborhood caused a lot of flak," says Lisa Piper, a Staten Islander and a recreation therapist who used to work with the women of 48 AB. "The neighbors didn't like it, but eventually they began to talk to the residents and get to know them." The happy climax came two Christmases ago. "A couple of people brought over a huge gingerbread house and a fruit basket," she says. "The residents here were delighted."

Tonight what's on tap at 48 AB is a combination Christmas-New Year's

celebration with the men from 47 Executive Way—the apartment next door. In one room some of the residents, including Sally, Rose and Susan, gather to fashion sparkling papier-mâché ornaments out of Styrofoam balls and red and green foil. Marcia shuttles back and forth between the craft room and the refreshment table, toting chocolate-chip cookies, cups of vanilla ice cream and steaming flasks of hot cocoa. Mary alternates between urging some of the shyer residents onto the dance floor and clamoring for a counselor to play Michael Jackson on the stereo. Jean claps her hands in time to the pounding disco beat.

Christmas at the old Willowbrook wasn't terrible, recalls Katy Tucker. The buildings were decorated, and there was a tree in each one. The tragedy, she says, was that the makeover was only cosmetic, and once Christmas was over, Willowbrook reverted to form. "I stopped by one of the Willowbrook buildings the other day," says Marie Ortiz, "and you know, it might sound crazy, but I can still hear the kids crying out. When I worked there, I used to cry too."

Ortiz isn't crying anymore. Nor are her "kids." "This home is filled with peace and love," she declares.

Come to think of it, kind of like Christmas itself. ■

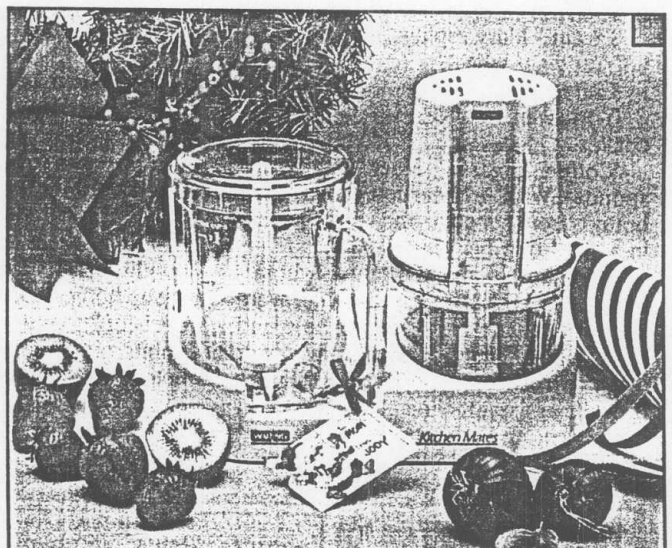


THE ONE-OF-A-KIND GIFT.

■ Waring's Hot Dog Express — the 90 second hot dog cooker — is the perfect solution to all your gift-giving challenges. Give the gift they'll relish all year long.

WARING

Waring Products Div., DCA, New Hartford, CT 06057



THE TWO-IN-ONE GIFT.

■ Waring KitchenMates is actually two versatile gifts in one compact countertop appliance. Great for all the blending and chopping chores in any ho-ho-home.

WARING

Waring Products Div., DCA, New Hartford, CT 06057