

Staten Island

Sunday Advance

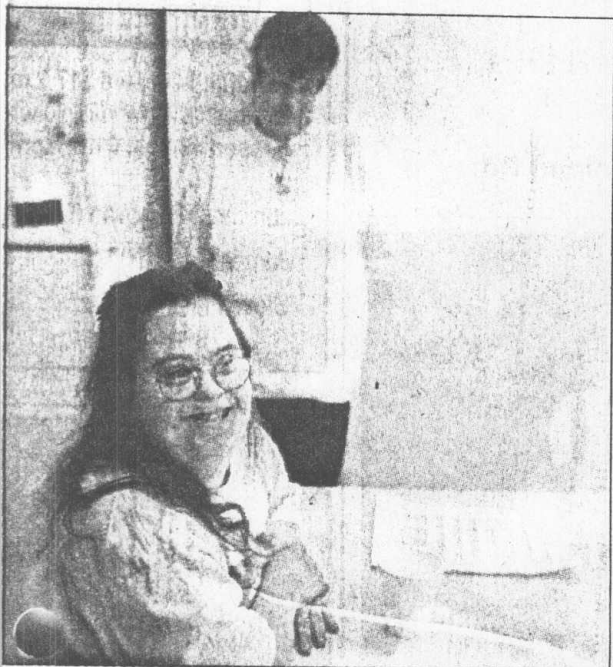
APRIL 16, 2000

SPECIAL REPORT
LIFE AFTER WILLOWBROOK

Inside a home for the retarded



Stacy cradles Oreo, one of two house cats who share her West Brighton residence.



ADVANCE PHOTOS ■ ROB SOLLETT

In the kitchen of her West Brighton residence, Lynn smiles as resident manager Kathy Denmark stands in the background.



Toni, a resident of A Very Special Place, Dongan Hills, strikes a pose in the back yard.

FIRST IN A FOUR-PART SERIES

- TODAY A vulnerable population
- MONDAY Questions about staffing
- TUESDAY Heart-wrenching decisions
- WEDNESDAY Do they fit in?

The developmentally disabled have the same rights as the rest of us, but they are often treated like they don't.

By MICHAEL PAQUETTE
ADVANCE STAFF WRITER

It's 5 o'clock on a typical weekday afternoon.

Toni shoots a few backyard hoops in Dongan Hills with a couple of her housemates before sitting down to a hot dinner of beef stew and mashed yams.

In West Brighton, Mark, who just got home from his job as a church custodian, checks on the lemon basil chicken simmering in the oven as Stacy, one of his housemates, fills a pot to boil rice.

Down in Rossville, Ray begs off table-setting duty with an abbreviated excuse — "Too tired," he says, wagging an index finger — but three of his housemates eagerly take up the slack.

Welcome to the world of the developmentally disabled 25 years after the signing of the Willowbrook Consent Decree, the landmark legislation that laid the groundwork for national reforms in the care, education and housing of people with mental retardation and other developmental disabilities.

Gone are the shocking images of institutionalized men and women lying naked on the floor in their own filth and feces. Vanished are the bone-thin specters slumped on bare wooden benches, picking at raw body parts for stimulation; or hugging themselves for comfort; or incessantly rocking to bring rhythm to a colorless day.

Today, the vast majority of the developmentally disabled live like Toni, Mark, Stacy and Ray — in groups of two to 14, most under the guidance of direct support staff, in cheery, spic-and-span apartments and houses in regular neighborhoods.

The more severely disabled keep busy by day with organized educational and recreational programs.

Their free time is spent listening to music, playing card games, watching videos or quietly sitting in the late-afternoon sunshine.

Many of the mildly and moderately disabled have full- or part-time jobs: They are office and grocery clerks, kitchen aides and fast-food workers. Others attend vocational and training workshops. At home, they are all self-empowered: planning their menus, cooking their meals, doing household chores, running personal errands, going out for pizza, and even dating.

"The goal is independence," says Kathy Denmark, manager of a West Brighton house for 10 mildly and moderately mentally retarded adults. "We try to get the residents to make as many decisions as possible, to include them in the decision-making process."

To be sure, snake pits across the nation faded into history soon after the horrors of the Willowbrook State School (now the site of the College of Staten Island) were thrust into the national spotlight in 1972 and lawmakers quickly set in motion the legal framework to depopulate state-run institutions: a vulnerable group long shunned by Americans obsessed with vigor and perfection.

The jargon has evolved, too. Human service workers now talk of "consumers" who live in "community residences" — another testament to the determination to erase institutionalization's ugly past.

Thirty years ago, some 27,000 developmentally disabled New Yorkers were warehoused in places like Willowbrook. Now, just about 1,000 remain in developmental centers, according to the state Office on Mental Retardation and Developmental Disabilities (OMRDD).

But the push is on to move them — as well as thousands of others now living with aging parents — into the wider community.

"They have the same rights that all of us do," says Maureen Brennick, associate director of A Very Special Place, Inc., a private, not-for-profit human services agency based in Dongan Hills. "We are all protected by the Constitution."

In the next four years, about 40 community residences for some 200 developmentally disabled Staten Islanders will join the 127 residences now scattered across the borough, local human services providers say.

The expected increase is due to a new state initiative — called New York State Creating Alternatives in Residential Environments and Services (NYS-CARES) — unveiled by Gov. George Pataki 18 months ago to phase in enough communal living space for thousands of New Yorkers who have been languishing on a massive waiting list.

“
We want to be
like everybody
else. We want to
be liked.

”
— Andrew, 23

Not always welcome

Yet despite laws such as the Willowbrook Consent Decree, the Americans With Disabilities Act, and NYS-CARES, some Islanders — to the consternation of the human services community — still fiercely oppose the establishment of community residences in their neighborhoods.

"Why isn't it the same for them?" Ms. Brennick asks rhetorically. "If I want to buy a house or live with a group of friends, the neighbors don't get a chance to vote on me."

Indeed, in the latest local brouhaha, Community Board 3 soundly rejected last month a proposed community residence for six mildly to moderately retarded adults in a quiet cul-de-sac in Greenridge.

William D'Ambrosio, the chairman of the Human Resources Committee that recommended the board oppose the plan, had argued the presence of the residence would "alter" the environment and "hamper

the fundamental goal of socialization and integration" of the residents into the community because of the relatively remote location of the house and the "deep-rooted and intense resistance of the community."

But at no time, opponents insist, was the presence of the residents themselves an issue.

"We are not a prejudiced community," says Karen Petrosino of Greenridge. "We are a well-educated community looking out for the well-being of our families. Should we let anybody come and do anything they want where we live and our children play without asking any questions?"

Objections generally include increased traffic

flow; the fear of plummeting property values; and the influx into the neighborhood of low-paid staffers who are not required by state law to undergo drug tests or criminal background checks.

However, many local human services providers say privately that fear of the developmentally disabled, borne out of ignorance, is the primary motive for protesting.

"It is about misinformation," says Joan Petersilia, a professor of criminology, law and society at the University of California, Irvine, and an expert on mental retardation. "The community perceives that mental retardation is mental illness."

Concord resident Andrea Cocozza, who opposes the establishment of a community residence slated for her block, admits the confusion.

"You don't know who you are getting in there," she says. "When I see mentally anything, I worry about that. Who knows what kind of mental they are talking about? It scares me a little bit."

What are developmental disabilities?

Developmental disabilities are mental impairments resulting in an IQ less than 70 (average is 100). They usually become evident before age 22 — and often much earlier — leading to lifelong limitations on learning, working and physical movement.

Mental retardation, autism, cerebral palsy, epilepsy and other impairments of the brain and central nervous system are included under the developmental disabilities umbrella.

Nearly 2 percent of non-institutionalized Americans are developmentally disabled. Of those, about half are retarded, according to the American Association on Mental Retardation.

There are two types of developmental disabilities, which can occur before or after birth: Organic disabilities are genetically or biologically based; non-pathological disabilities arise from adverse environmental conditions.

Down and Fragile X syndromes are genetically based organic disabilities; biologically based organic disabilities include those that spring from exposure to certain infections, such as neonatal herpes, streptococcus, and bacterial meningitis.

Non-pathological disabilities can develop in a fetus if a woman uses drugs or alcohol during pregnancy; in a newborn, if he or she suffers from a lack of oxygen during birth; or in a child, if he or she is exposed to certain contaminants, such as lead. Child battering, accidental head injuries and near drowning also can cause developmental disabilities.

Still, Ms. Petersilia says, many confuse mental retardation, which basically is low intelligence, with mental illness, which can greatly impact moods and emotions and can lead to violent outbursts.

"Mental retardation is about intellect, but you can

be brilliant and be mentally ill," she says. "(Mental retardation) simply means low-intellect functioning. It is not about erratic behavior. In fact, routine is important (to the mentally retarded). They love routine. It's a very different model, but unfortunately in the public's mind they are one and the same."

"People with mental retardation and developmental disabilities are very much like you and me," says Deborah Rausch, a spokeswoman for the OMRDD. "They have the same goals, the same needs and the same desires that everyone else does. There's no reason to think that they would behave in any other manner than you or I."

Other common characteristics of the developmentally disabled can include childlike thinking; slowness in learning; little long-term perspective; and the inability to understand the consequences of actions.

They tend to be eager-to-please followers who trust authority without question.

"Developmentally, they are not the same as they are physically and chronologically," says Donna Long, director of community relations and development for On Your Mark, a West Brighton-based human services agency. "As there are differences in levels of intelligence in all of us, so it is with them."

Some common traits, she says, include "kindness, innocence and sincerity."

No more likely to commit crimes

Because the developmentally disabled tend to take circumstances at face value and can be manipulated easily, they are more likely to become crime victims than crime perpetrators.

"Studies have shown their rates of crime are similar to those of non-disabled persons, and consist mostly of less serious felonies and property offenses," says Ms. Petersilia. "The data are consistent. (The mentally retarded) have extremely low rates of crime."

In fact, she says, a developmentally disabled person is nearly 11 times more likely to become a victim of sexual assault than a non-disabled person and is almost 13 times more likely to become a robbery victim.

Crimes against the developmentally disabled are divided evenly among those committed through "service provider contact," such as house staff and transportation workers; immediate family members; and strangers and "others," usually housemates who do not give or are unable to give consent to sexual activity, Ms. Petersilia says.

In the wider community, she adds, the developmentally disabled are most likely to find themselves in trouble by their proclivity to hug, a common practice encouraged by many in the human services field to reinforce love and acceptance, much like one would do with a child.

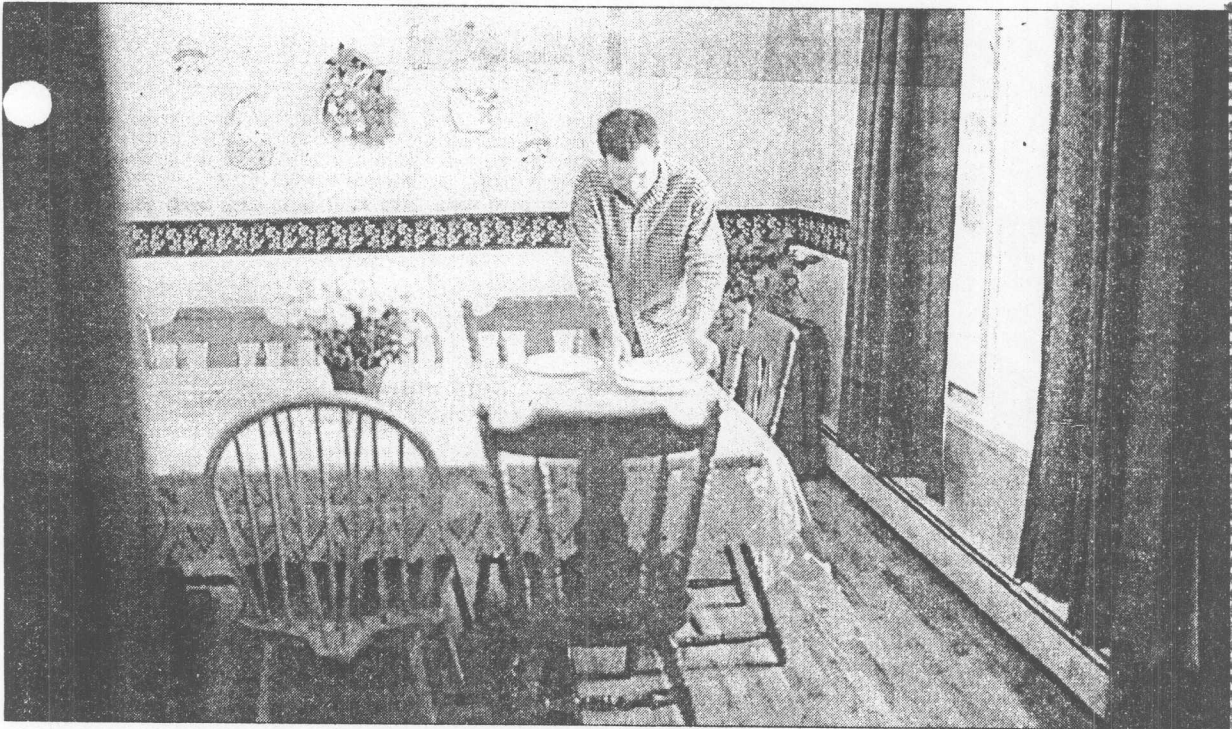
"I think sometimes they are inappropriately affectionate," Ms. Petersilia says. "They use physical touching much more than people who are not disabled are comfortable with."

But, she adds, she is not aware of any case where hugging a stranger as a greeting or sign of affection has led to an overt sexual act.

Human services providers and the developmentally disabled themselves insist their presence only enhances a neighborhood.

"People should understand that they are lucky to have us as neighbors," says Nancy Santanello, manager of a Rosville house for 10 developmentally disabled men. "It's much more important for us to follow the rules and we have a much higher standard of living that we have placed upon ourselves so that we will be accepted."

Says Andrew, 23, who calls his four years in a West Brighton community residence "the best years of my life": Community residences are "all about togetherness. ... We want to be like everybody else. We want to be liked."



ADVANCE PHOTO ■ ROB SOLLETT

Andy begins to set the table for dinner at the Hiby/Selkirk community residence in Rossville.



An avid movie fan, Dekay House resident Mark enjoys a relaxing moment after completing his chores.



ADVANCE PHOTOS ■ ROB SOLLETT

A Very Special Place resident Ricky plays basketball in the yard of the community residence on Benton Avenue.