

SPECIAL REPORT
LIFE AFTER WILLOWBROOK

One of life's most gut-wrenching choices

Dozens of Island parents have made — or will soon make — the tough decision to move their adult children into community residences for the developmentally disabled

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As a jurist, Civil Court Judge Philip Straniere has ruled on dozens of emotionally charged eviction cases and personal injury claims.

But the Livingston resident and his wife, Jennifer, made perhaps the most difficult decision of their lives just two weeks ago, when they moved Gregory, their autistic son who will turn 20 next month, into a community residence for the developmentally disabled.

"You always think you should be able to take care of your own child," says Straniere. "But at some point you decide, is it beneficial for him to stay at home?"



ADVANCE PHOTO ■ ROB SOLLETT

Judge Philip Straniere and his wife, Jennifer, visit their son, Gregory, at the Cebra Avenue Community Residence.

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Since the mid-1970s, hundreds of Staten Island parents have made similar heart-wrenching decisions. Currently, more than 800 teens and adults — all Islanders with developmental disabilities such as mental retardation, autism, epilepsy and other impairments of the brain and central nervous system — live in community residences scattered throughout the borough.

And with more than 200 developmentally disabled adults awaiting similar living arrangements — and scores more now living with aging parents and family members — dozens will soon face the same tough choice as the Stranieres.

It's a delicate balancing act,

to be sure.

For most parents, the decision to seek a community residence means parting with a child they have sheltered and nurtured with intense devotion for decades, sometimes at the expense of other siblings.

It requires weighing the child's special needs against their own personal attachments and their inability to deliver needed services and recreational opportunities with peers that community residences provide.

"It was a very hard decision," admits Elaine Gregoli, of Huguenot, whose daughter, Lynn, 29, has lived in a community residence in West Brighton for eight years. "As a parent, nobody takes care of your kid better than you. But I felt at some point you have to let go."

Like dozens of aging parents of developmentally disabled

children, Imelda Doherty, 67, wonders how much longer she can care for her son, Brian, 35, who has Down syndrome.

Even before her husband died four years ago, the Dohertys had placed Brian, who works part-time sealing utensil wrappers in plastic bags, on the waiting list for a community residence.

"It's heartbreaking for any parent in having to have a child leave home," says Mrs. Doherty, of Grant City, noting her son has lived his entire life with her.

"[But] I'm concerned about Brian's future," she adds. "I'll be getting on in years and I want to make sure he's taken care of. I want him in an environment where he can be with others like him."

Reluctant to burden siblings with the responsibility of caring for a developmentally disabled brother or sister, parents say community residences — which are run by the state or a state-authorized not-for-profit agency and typically house about eight people — are a godsend.

Mrs. Gregoli says her daughter Lynn, who has Down syndrome, has grown more independent and communicative during her eight years in a community residence. Lynn now works as a kitchen aide in a nursing home and shops alone in neighborhood stores.

"What I found out very quickly is Lynn grew up when she went to a group home," says Mrs. Gregoli, who works for YAI New York League, an agency for the developmentally disabled in Manhattan. "She became much more outgoing and much more talkative, because she has peers she can talk to. She really loves it."

Many parents say moving into a community residence is a logical step in their child's development. They often think about placing their child on a community residence waiting list — a wait that can take years — when he or she is in their late teens or early 20s, around the same age siblings might be heading off to college.

"The natural thing would be for him to move out at that age," saysorraine DeSantis. Her son David, who is autistic, entered a Dongan Hills community residence more than two years ago at age 20.

Isabelle Schelker of Port Richmond cites loneliness and a chance for a better future as reasons for wanting her mentally retarded son, Chris, 19, to live in a proposed community residence on End Place in Greenridge.

"What's his life going to be, star-

ing at his mother for the rest of life?" says Ms. Schelker, a single parent of two other grown children and an outspoken advocate for the developmentally disabled. "There's been a lot of joy in my life with him, [but] I think he deserves to have the opportunities his brother and sister had to be free and independent."

Not everyone is so convinced.

Last month, at a Community Board 3 meeting, scores of residents cheered when the board rejected the End Place proposal. (The state Office of Mental Retardation and Developmental Disabilities will make a final determination on the site.)

There, as in Community Board 1, where residences recently were approved in Westerleigh and Sunnyside, dozens of neighbors oppose the sites. Common concerns include the potential for declining property values, and parking, noise and sanitation problems, which, opponents say, are associated with community residences.

Parents of the developmentally disabled say the opposition is misguided, often linking — incorrectly — their children with the emotionally disturbed and mentally ill.

While the mentally ill can be subject to mood swings and emotions that may, on occasion, lead to violent outbursts, the developmentally disabled are typically placid, friendly, trusting and not prone to violence, they say.

"I know there's been problems whenever a community residence comes up," says Mrs. Gregoli, "but I think once they see these are not schizophrenic people who are going to kill their kids and molest their grandmothers — which has been said — they see these are real people who lead very normal lives, but just need a little more help than the average couple next door."

Moreover, human services advocates claim community residences are well maintained, employ round-the-clock staff, and host hands-on parents who visit their children several times a week. While parents say they would not hesitate to act if something was amiss, few say they find reason to intervene.

Toni and Nick Cutrone, however, are an exception.

Recently, the couple received approval to build a community residence in Willowbrook for five developmentally disabled men, including their son, who currently lives at another Island residence.

Mrs. Cutrone, saying it would be "counterproductive," declined to

specify why she wants to operate her own community residence.

Still, most parents report their children have prospered in the borough's community residences.

Many community home residents work — typically at low-paying jobs in the fast-food or service industries — while others attend vocational workshops. Nearly all have chores in the house. The wages, training and responsibility instill independence in the developmentally disabled they might not have attained at home under doting parents.

Mrs. Gregoli said her daughter, Lynn, and her housemates have planned several vacations, including a self-paid cruise this August to Puerto Rico and the Caribbean.

"It's the best thing I ever did for her," she says.

Yet for all the success stories, the decision to separate from a child is never an easy one.

Judge Straniere admits he has second thoughts. But Gregory, who doesn't speak and so cannot verbalize his feelings, apparently is adjusting to his new home.

"Is he going to feel abandoned? That's the biggest fear," Straniere says.

Still, Straniere believes he made the right choice. And, he says, the options today are far better than they were three decades ago, when his son would have been placed in what became known as one of the country's most nefarious institutions for the mentally retarded.

"You're taking somewhat of a leap of faith," he says, "but 30 years ago he would have been in Willowbrook."



ADVANCE PHOTO ■ ROB SOLLETT

Isabelle Schelker of Port Richmond is trying to get her son into a community residence.

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THE ISLAND



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Lynn Gregoli with her mother, Elaine, in front of the Community Home for Developmental Disabilities in West Brighton.