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Living and learning with a retarded child

Parenthood is bittersweet for those with mentally retarded children.

Nobody knows that better than people like Matthew-Michael Lumetta, Polly Panzella and Lorraine Horenburg.

Each is the parent of a mentally retarded son. Their situations are somewhat similar: Their sons are all in the mid-20s, they were raised at home rather than institutionalized, and all three families are Staten Island residents.

Moreover, each of the families dealt with retardation at a time when the problem was ignored by society.

"Years ago, parents were ashamed," said Thomas Horenburg, Lorraine's husband. "Today, parents realize that they are not alone."

"A lot of parents are coping with it now," added Mrs. Horenburg. "There's more help available from agencies. That wasn't there for me. When Charlie was born, the first thing out the doctor's mouth was 'put him away.'"

The stories of these parents illustrate some of the challenges posed by caring for the mentally retarded. Moreover, they remind us that for hundreds of families, reforms in care of the retarded is a deeply personal issue.

Matthew-Michael Lumetta was as cheery as the weather on a bright, sunny afternoon at Staten Island Developmental Center.

The campus was holding its annual summer festival, and Lumetta was a guest of honor in recognition of his work with the handicapped. Even beyond that, Lumetta took special delight in observing the pleasure of the clients as they sucked on ice cream cones and wiggled to music blasting from loudspeakers.

"I remember the first time I came to this place," he said. "It was the same week my son was born."

Matthew Lumetta, now 24, was born with Down's syndrome, one of the most common forms of mental retardation.

"I didn't know anything about Down's syndrome," he said. "The first thing I did before I brought him home was to find out everything I could."

"I went to our parish pastor and he told me to talk with other families in the parish who had DS children. But when I called on

these families, they all refused to talk to me. They were ashamed. Things were different 20 years ago."

So, Lumetta went to the SIDC, then called Willowbrook State School, to talk to the director about Matthew's future. "He told me to take my baby home and to love him," said Lumetta. "I never had any thought of placing him, just as long as he had no disabilities which needed constant care. Luckily, it worked out."

"He's high-functioning — he's like an 8- or 9-year-old in certain areas — and my three daughters loved him, taught him everything, took him for walks."

His daughters made raising Matthew easier, but some problems have been unavoidable, noted Lumetta.

"DS kids have the same emotions as normal children — they go through puberty and adulthood, they talk about marriage. But they can't have all these things and the frustrations come out in different ways. In my son, it comes out as stubbornness. He's very stubborn about things," said Lumetta.

Matthew still lives at home and is employed at a sheltered workshop.

"As for the future? You talk about this, but the future arrives before you plan," said Lumetta. "I'm lucky to have daughters and son-in-laws that have assured us that he will be provided for after we go."

The daughters have the option of moving Matthew into one of their homes or placing him in a group home. "Whatever is best at that time," said Lumetta. "I trust them."

Whatever the difficulties involved in caring for Matthew, Lumetta expresses no bitterness or anger. "We can't pick and choose our children," he said. "And we have to do what is best for them."

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The hardest decision of Polly Panzella's life was moving her son away from home.

The Panzellas placed Benny Panzella, now 25, in a non-profit residential school in upstate New York five years ago. The facility is not an institution, Mrs. Panzella takes great pains to note, and the 87 residents are housed in group homes.

"I wanted him to be free within a protected environment," said Mrs. Panzella. "He loves it."

Benny spent most of his life at home. In the early years, Mrs. Panzella figured she could do a better job than any residential school or institution, even though keeping Benny at home became, at times, a hardship.

"I remember putting him in nursery school and the tuition matched our rent," she said.

"When Benny was growing up, the state didn't offer much for kids who were not in institutions, so we made our own programs. The mothers helped each other."

As Benny grew older, his parents began to consider placement. "You have to understand that Benny is 6-foot-2 and he intimidates people," said Mrs. Panzella. "Then one day at Macy's he was reaching for a record album and he accidentally touched this woman's breast and she slapped him. It was one of the first times I saw Benny cry with real tears.

"That's when I realized I was being selfish by keeping him with us. I really didn't want him to suffer by living at home.

"Putting him in school was the hardest thing we ever did, but I knew we had to do it."

Benny's future at the school seems secure, and Mrs. Panzella takes comfort in that.

"The mistake that most parents make," she said, "is not realizing that they won't live forever."

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Lorraine Horenburg loves all her children, but Charlie is clearly her favorite.

"Anybody can pick on any four of my other children," she said. "But nobody picks on my Charlie."

She has felt that way ever since her son was born 27 years ago, the third of five children. "I knew Charlie was retarded from the day he was born," said Mrs. Horenburg. "He had that look to him. When I asked the pediatrician about it later, he told me that Charlie was 'mental.' That's all he said."

The Horenburgs never considered placing Charlie in an institution — "He's mine. That's it," his mother says fiercely — and tried to give the boy as average a childhood as possible.

It helped that Charlie is only mildly retarded; while he cannot read or write, he was still able to play games with the neighborhood kids and help around the house. "He was treated just like all the other kids," said Mrs. Horenburg.

In time, Charlie graduated from the public school's special education program and an occupational training center. He now works in a sheltered workshop.

He lives at home, and his parents eschew any idea to the contrary. They voice disdain about

the quality of care elsewhere, including group homes, and say they will never abdicate their responsibility of Charlie to the state.

"The government hasn't been willing to do anything for me and I haven't asked them for anything," said Mrs. Horenburg. "I wouldn't want anything for them.

"Charlie will always live with one of us. The other kids are all very content with that idea. We told them one time that we'd have to put Charlie in a group home when we go and they wouldn't hear of it.

"We can take care of him better than others. Even if Charlie wasn't as high-functioning, we still wouldn't put him in a group home. God gave him to me for a reason."

When pressed, the Horenburgs admit that life with Charlie is not always easy. As a child, he was the subject of cruel teasing. As an adolescent, he was blamed for every prank and accident in the neighborhood. Now there are other difficulties.

"He wants to get married someday," said Tom Horenburg, Charlie's father. "Oh, boy. How do you cope with that?"

But the Horenburgs prefer to stress the positives over the negatives.

"I'm proud of Charlie — not proud of the fact he's retarded — but I'm proud of him," said Tom Horenburg. "A lot of people say we have a cross to bear. We don't have a cross to bear. God gave us a saint."

— JULIE MACK