

A. J. Conance - 7/27/83

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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