

# Retarded child's parents face special problems

When people think of retarded children they often forget another side of the issue: the child's parents. In today's Close Up, staff writer Tim Anderson examines what it is like to be the parent of a retarded child.

by Tim Anderson

"Finding out about Elizabeth was really a shock. We had been expecting a nice, normal baby. It was hard on us, but I know we could never give her away. I could never do that."

Elizabeth is a 2-year-old mongoloid child and that's her father Terrance Schmitz, talking.

"There are few things in life like that feeling when you find out your child is retarded," Ms. Schmitz said. "It always happens to someone else and you just don't think it will ever happen to you."

Elizabeth's apparent mongolism was discovered the day after she was born, Schmitz said. "It was really rough for both of us, seeing that nice, little baby lying there, and then finding out she's retarded."

The Schmitz's then went to Omaha where a genetic work up was done. Three weeks later the mongolism was verified.

"The doctor told us what was wrong and what our alternatives were," Schmitz said. "We could keep Elizabeth as our own child, or we could give her up and let her be institutionalized."

"We could never have done that, but some couples do. They just write it off as a bad chapter."

According to Schmitz, mongolism is a form of clinical mental retardation fated from the moment of conception. The trait runs in Schmitz's family. He, his father and three brothers are all carriers.

Schmitz has 45 chromosomes, instead of the complete 23 pairs. Elizabeth has 47; the extra one is responsible for the retardation.

"Elizabeth is going to the human development program at LOMR now," Ms. Schmitz said. LOMR is the Lancaster Office of Mental Retardation. There Elizabeth is instructed in putting puzzles together, feeding herself and other daily skills such as walking up stairs, Mr. Schmitz said.



Although Elizabeth someday could be ready for a normal school, her father said it is doubtful that she will ever attend regular classes.

Schmitz is student teaching in special education at Lincoln's Hayward School where he works with trainable retarded children. He said some programs allow a retarded child to go to a specific class, such as physical education, and then return to her special education classroom.

Schmitz and his wife said they are not overly worried about problems with Elizabeth as she grows older, such as her desire for a driver's license or privileges given to normal young people.

"For some reason, it seems that mongoloid children tend to stick around home more," he said. "The kids I teach never seem to get together on weekends and play records or anything."

Ms. Schmitz agreed: "If those problems do arise, we'll have to meet them at that time. There's really no sense in worrying about them now."

When the Schmitz's were told of Elizabeth's condition, their doctor recommended that they get in touch with the parents of other retarded children so that they might find some insight into possible problems.

"We found out that having a daughter who was a mongoloid was nothing compared to the problems some people have," Schmitz said.

Besides the added concern, parents of retarded children often incur special costs for the treatment of their child.

However, because Schmitz is a student, much of the additional cost for Elizabeth was "somehow written off."

The Schmitz's have another daughter, Jennifer, 6

months, who is normal. Before Jennifer was born, tests were run on the fetus to see if it was to be a normal baby.

The test, amino synthesis, is foolproof in finding mongolism and other forms of mental retardation, Schmitz said.

If the test had shown the baby also was to be a mongoloid, the Schmitz's would have faced a serious decision—to go ahead and have another retarded child or to terminate the pregnancy.

"I really don't think we could have gone through with having another retarded child," Schmitz said.

Ms. Schmitz said if they had planned on having another retarded child "there would have been no reason for the test at all."

The Schmitz's said they love Elizabeth very much, and, as Schmitz puts it: "There is a certain loveliness in Elizabeth that you won't find in other children.

There's an innocence and simplicity, almost a reflection of God.

"When she was born, I went to the library and checked out all the books I could find on mental retardation in order to find out as much as I could about it. We had a public health nurse stop by, too," he said.

"But most important was what we learned from the other parents. We never got any 'I'm so sorry for you' type reaction from them, because they all knew what was really going on."

Depending on her abilities, the Schmitz's plan to keep Elizabeth at home until she can be independent, or, at least "partially independent."

"We'd like her to be able to live alone, without us, and be able to have a job of her own really doing something," Ms. Schmitz said.

"We want Elizabeth to be taxpayer rather than a tax shelter," Schmitz said.



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