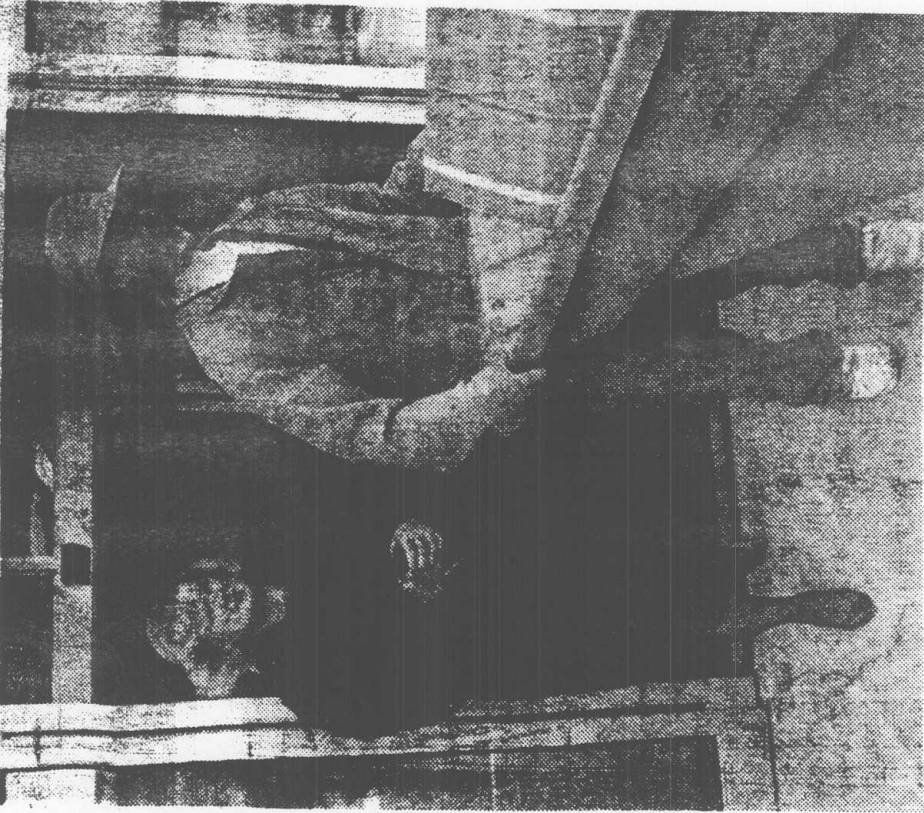


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A parent's toughest choice



ADVANCE PHOTO/HILTON FLORES

Linda Coull watches her son, Eric, work at the United Cerebral Palsy Center in Port Richmond.

Placing children with strangers

By EILEEN AJ CONNELLY
ADVANCE STAFF WRITER

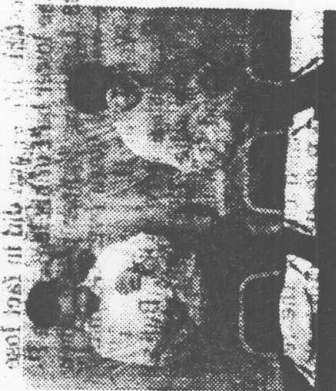
"The most difficult thing that parents can do is place their children with strangers and depend on strangers to care for them."

Polly Panzella knows firsthand how difficult that is, because her son, Benny, 33, lives in a group home on the Island. Although sending Benny to live away from the family home in West Brighton was difficult, Mrs. Panzella doesn't regret the decision.

"He will always have to have someone taking care of him," she said matter-of-factly.

Living in a group home for the past year and a half, her son has learned to be more independent. "Benny has grown tremendously," Mrs. Panzella said.

Linda Coull of Graniteville has a similar opinion about the group home where her 21-year-old son, Eric, now lives. Having him live "on his own" has given Eric a chance to gain independence and skills he probably would never have developed if he had re-

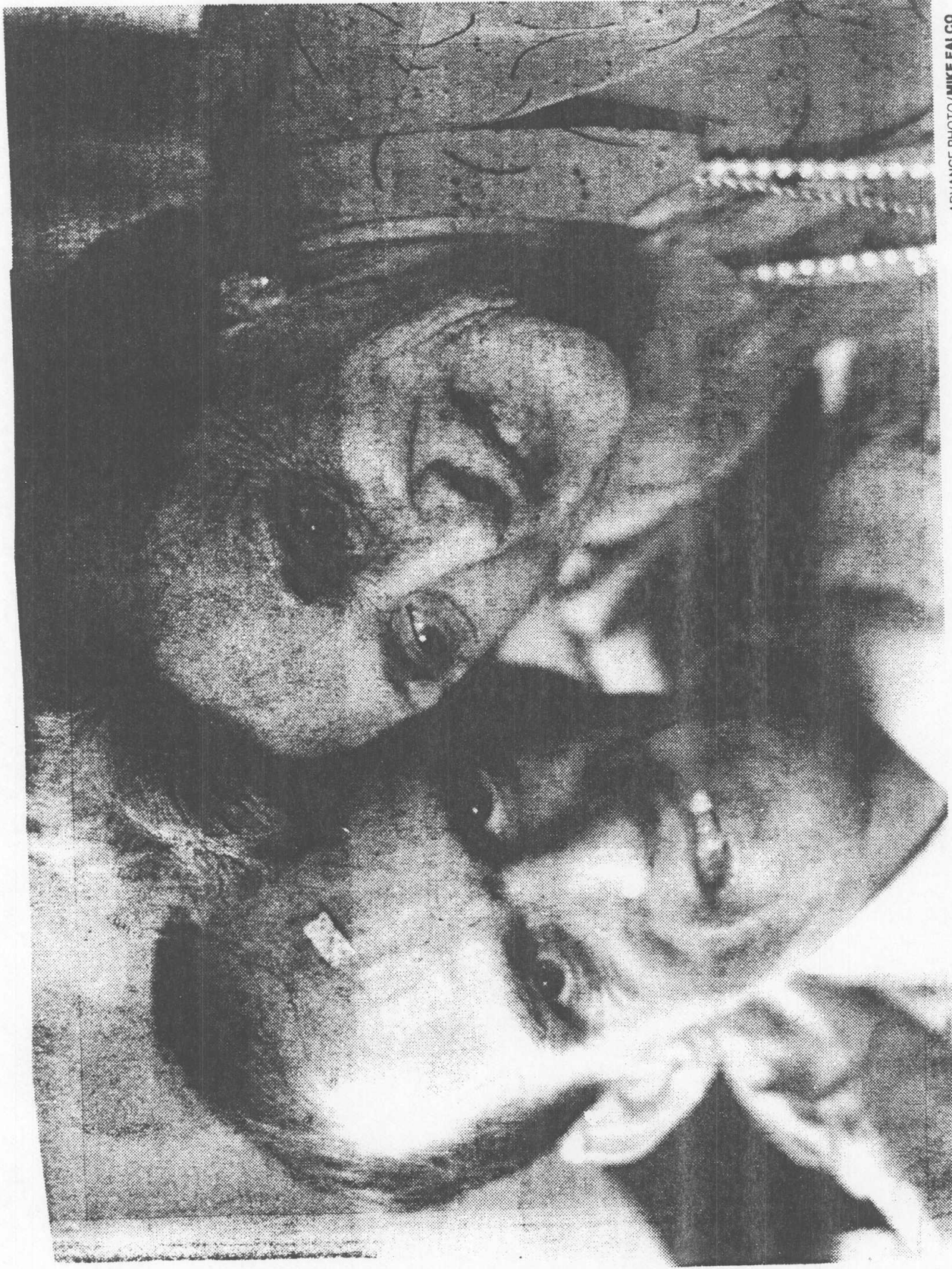


Group home Dilemma

mained with his mother, she said. Not every family that includes a person with developmental disabilities opts for the group home solution. But for the families who do, group homes often provide answers to troubling problems, as well as opportunities for their loved ones that other options might not provide.

"In my case I don't have an alternative," said a mother who asked that her name not be revealed. "My son is low functioning and needs to have someone there. He needs to be cared for."

(See CHOICE, Page A. 26)



ADVANCE PHOTO/MIKE FALCO

Benny Panzella visits with his mother, Polly.

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"There are plenty of retarded individuals that are higher functioning that can stay in the community, in parents' homes or with other family members. There are even higher functioning ones living in apartment settings," she said. But for her 36-year-old son, the only alternative to an institutional setting is a group home.

As parents grow older, they worry about providing care for their children after they die. That is one of the reasons Richard Montuori will soon be moving into a group home in Brooklyn.

"We as parents are looking for something or someplace where we know he is going to be taken care of," said his mother, Mary Montuori.

"There's going to be a time when he is going to outlive us," Richard's father, Carmine, added.

"Our other children are married and have their own children and in that way, they're settled," Mrs. Montuori said. "We'd like to know that Richard is settled, too."

Richard, 33, lived in the former Willowbrook State School for about two years before that infamous institution closed. Although the agreement between the state and the families of Willowbrook residents said the residents would all move to group homes, there are some like Richard still living in large institutions like the Brooklyn Developmental Center.

The Montuoris said they were hoping Richard would be placed in a Staten Island group home so that he would be near his brother and sister, who live in South Beach and Huguenot, respectively. But since an opening in a Brooklyn house has become available, the couple has decided to let Richard try that.

"We wanted to make sure he had a place," Montuori said.

Parents know that group homes cannot provide the same sort of living conditions their children would have if they never moved away. "You're never going to find the best, but you can do the best you can," Mrs. Panzella said.

"It's not like home," Ms. Coull agreed. But she pointed out that if Eric weren't handicapped, the living conditions he might experience at age 21 would probably be less than what she would provide anyway. "It would be much worse if he were 21 and living with a bunch of the guys."

Having their children live in group homes does not mean that parents no longer have responsibility for them. "You're not giving up your job as a parent," Ms. Coull said.

Mrs. Panzella said parents have to be aware of what is going on at the home where their child lives, to make sure he gets the best care possible. Even in the best homes, problems arise, and parents have to advocate for their children.

One of the most recurrent problems is staffing. Mrs. Panzella said the people who work in group homes are often not as attentive as she would like them to be. She said parents often complain of staff members sleeping or watching television instead of interacting with the residents.

The mother who asked not to be identified said a high ratio of residents to staff members can also lead to more personal issues, like whether or not personal hygiene is maintained.

If there are supposed to be three staff members at the group home and there are only two on any given day, it makes a big difference to the 10 or 12 residents, she pointed out. "Then the child is likely not to be as clean as they would have been," she said.

But Ms. Coull said she feels her son has to learn to care for himself as much as possible. And she pointed out, in the group home there are adult males who can

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help Eric with things like bathing. Concerns such as personal hygiene keep some families from choosing group homes. Helen Shkymba decided to keep her daughter, Ginger, at home in Princes Bay. After her parents die, Ginger is probably going to live with her sister and her family, Mrs. Shkymba said.

"I have nothing against group homes per se," said Mrs. Shkymba. She agreed they are the best choice available when children and parents must separate. But she said that having her daughter at home is no trouble, and she doesn't think Ginger, now 48, could adjust to living in a group home.

Mrs. Shkymba said she would worry that her daughter was not cared for as well as she is at home. Although Ginger is able to bathe independently, for example, Mrs. Shkymba said she does need to be supervised and assisted. "Who is going to take the time to do that?" she asked. "I don't know, maybe in a group home, they would."

Ginger attends a sheltered workshop, which she loves, and also is active in several recreation programs, Mrs. Shkymba

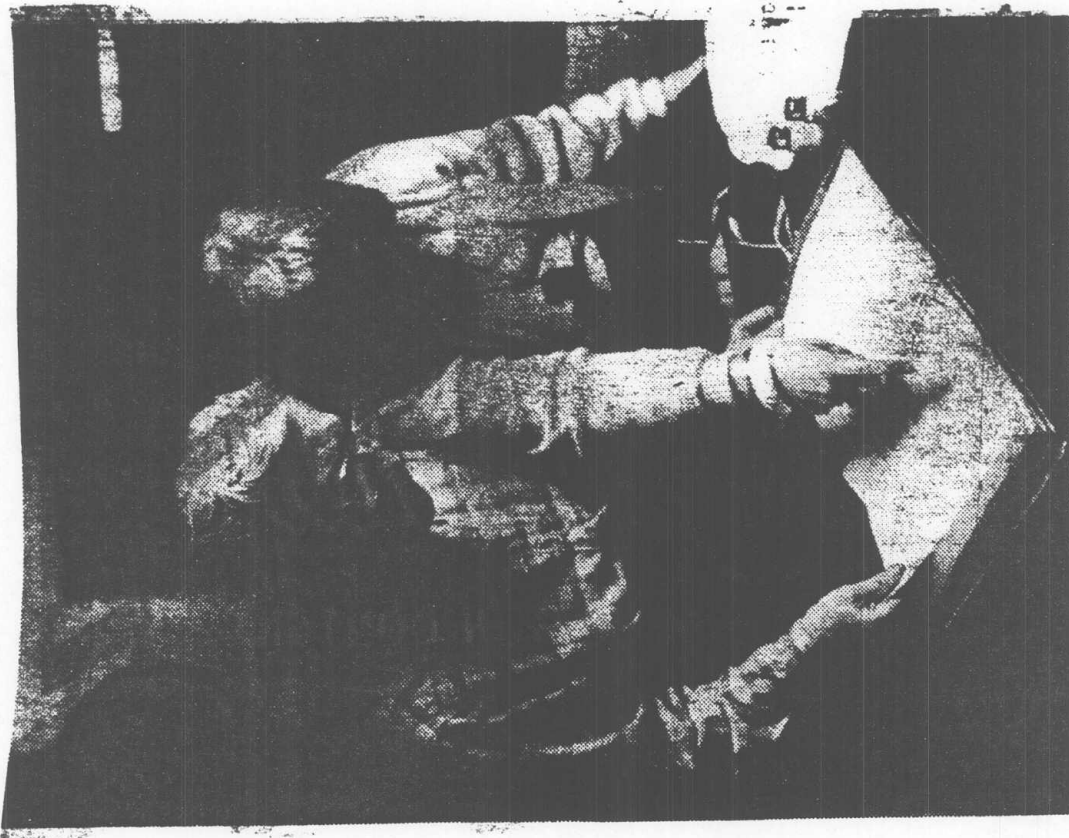
said. "We hardly see her.

Ginger did try to stay at a respite program last year while her parents were away on vacation, but Mrs. Shkymba said that after a few days, she became hysterical and ended up staying at her sister's home for the remainder of the week. It wasn't worth repeating that again this year, she said, so Ginger simply stayed with her sister.

Mrs. Panzella said her son likes to come back to visit his parents' home, but he also likes to go back to the group home. She said his visits are often cut shorter than planned because he asks to leave. Benny is very concerned about his housemates, she said, and often when their routines change. "They concern themselves with each other," she said.

Mrs. Coull remarked that people with developmental disabilities are much more accepting of each other than even their families are. "Part of what we do is forever try to make them into something normal," she said. "They accept each other much more than we do." "It's a very loving setting," she added.

— Last of a series.



ADVANCE PHOTO/MIKE PALCO

Ginger Shkymba shows her mother, Helen, what she has been doing in school.

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