

Group home lets Isabelle live life to her fullest

By CHRISTOPHER RINGWALD
ADVANCE SPECIAL WRITER

Isabelle Weiner, 38, lives on a quiet block in Brooklyn by the shore of Jamaica Bay. As an infant, Weiner was put in Willowbrook by a single mother unable to care for her and another handicapped sister.

Twenty years later, Weiner was transferred from Building 32 at Willowbrook to the first of several group homes. In 1985, she requested placement at her current home in Canarsie.

"That showed real initiative," said Rita Martin, who follows Isabelle's case and admires her progress.

Nine women live in the three-story detached house.

"The house for the people with the handicaps . . . or something?" A neighbor says, standing at her front gate on Conklin Avenue. "It's the one over there."

Neighbors originally fought the establishment of the group home. That happens everywhere, said Jo Massarelli of the Community Development Services Agency in New Hampshire. She evaluates programs and has established residences for mentally retarded people throughout the Northeast.

Today, neighbors and Weiner's group home coexist peaceably, which Massarelli said happens just as often once people meet each other. Threats made to employees of Weiner's agency, the Adult Retardate Center, were never carried out. Lost clients have been found eating cake and milk with neighbors, though generally, former ARC residence supervisor Laura Grinnell said, it is not a friendly area.

Inside, Fay, a cook at the house for six years, is preparing dinner. While chicken bakes, she sits with Carla and Mouschka watching TV. Weiner is out shopping with two other residents.

Fay's tenure is a long one; staff turnover is high. Residents see group home supervisors and counselors change several times a year.

"The agency wanted to move me," Fay said. "I refused; you should have seen the people here when they heard I might move. They cried and held on to me. I don't want to go, that's all they see, is people leaving. Staff comes and goes. No one ever stays with them."

Weiner, like Siegel, has had her current caseworker for less than a month. High

Life after Willowbrook

turnover fractures progress, mental health professionals say, especially when the client's primary relationships are with paid staff members.

"Relationships are the glue in our lives that keeps us together," explained Massarelli. "For the mentally handicapped person, the most vulnerable part of their lives can be unhinged by a funding or administrative consideration." Low pay and hard work discourage many workers.

Weiner bustled into the room in a cold blast of packages, overcoats and winter air. She is an alert woman wearing a smart overcoat and a skirt and blouse. At dinner, Elizabeth, a counselor, asked Weiner about her shopping.

"How much did you spend today, Isabelle?"

"I don't remember."

"I hope you didn't go over the limit I gave you."

"No, I just can't remember." Elizabeth turned to another resident.

"Cathy, how much did Isabelle spend?"

Cathy doesn't know and Weiner volunteers, "Not that much."

"Was it more than the \$5 limit I gave you?"

"No, maybe, I don't remember."

"Well, it must have been if you don't remember." Elizabeth concludes.

Weiner began to learn to budget her money after years of lessons from staff members, Grinnell said. Originally an impulsive spender, Weiner has saved enough to take trips to Colorado, California and, recently, Texas, where a sister lives.

Weiner turns to her other dining companions. "I bought things for sewing, for something to do. I make potholders. I'm not going bowling tonight, I have things to do here. I'll want a bath to relax myself, then wait for Ricky to call — that's my boy friend." Ricky is also mentally retarded, and lives in a nearby group home. She giggles. "You believe I'm waiting for a phone call from him?"

Weiner does not remember details and dates well but she does recall the man many former Willowbrook residents credit with their release.

In the outside world, Weiner has learned skills neglected at Willowbrook. Caseworkers applaud her personal ap-

pearance and care.

"I remember a retirement party for another client, and Isabelle came by herself," Rita Martin recalled with a smile.

"She was nicely dressed and brought flowers for the lady retiring. To look at her, you wouldn't have ever known. And you wouldn't have been able to imagine her in a place like Willowbrook."

Weiner strode down the street to the beauty parlor one Saturday afternoon. The hairstylist, Marianne, is one of the few neighbors Weiner knows. She can't name any others, and no one on the street greeted her. Massarelli points to exactly this type of situation as inadequate for true normalization.

"We may be integrating people physically, but not socially. When someone moves into a group home in an area, the PTA doesn't invite them to a meeting, the Welcome Wagon doesn't come to their homes, the church doesn't see them at services on Sunday. There is no personal meeting, face-to-face contact. We have not changed the institutional model, we just have smaller institutions." In her work, Massarelli involves neighbors in the lives and care of her mentally retarded clients. Most volunteer, some to teach cooking or help with personal finances or to simply talk.

Weiner works in a sheltered workshop run by her agency. She puts together pens, box games, and performs other assembly work. Whether she is learning skills there or at home to advance her independence is questionable. Weiner needs the protected environment and the company of her peers, Grinnell said. She doubted Weiner could manage in the workaday world.

"Isabelle is easily frustrated. She's fine when she knows what to do," Grinnell said, "but there can be outbursts." Weiner's more serious mood swings have moderated. She had a once-a-year cycle of psychiatric hospitalizations which, Grinnell said, has been broken by intensive counseling.

Weiner seems uninterested in living more independently. The consent decree requires that she be taught basic life skills, such as cooking, which, at the age of 38, she has not learned yet. All meals are prepared for her.

Further, Massarelli said, when clients in homes learn to cook, "they learn to



Originally an impulsive spender, Isabelle Weiner has saved enough to take trips to Colorado, California and, recently, Texas, where a sister lives.

cook for an army or not at all." She gave an example: "I visited a man in his group home once and he offered me iced tea. Well, I waited and waited and finally I went into the kitchen to see what took so long. He was in there making six gallons of it because that's the only amount he ever made living with 14 other clients." She shook her head, adding, "The system is designed to perpetuate itself."

Kendrick, the normalization project director in Massachusetts, said that the real problem is attitude.

"Now there's a trend toward reinstitutionalization," he said, "because people thought the institution was the problem and not the attitudes that created it. Just getting the people out has not solved the problem."

Kendrick and other normalization advocates insist that the best hope for their clients is to meet people in the community.

They cite evidence that isolation of the mentally handicapped increases the chances of reinstitutionalization. Kendrick looked to the community rather than staff members.

"Bureaucrats control these people's lives because no one else does. Until the community shares responsibility for what happens in the lives of the mentally handicapped, then the infantilizing of clients will continue."

(This is the third in a series of five articles. Tomorrow: Melita Diaz.)