

Leaving mental institution meant freedom and dreams

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On the day Martin Siegel cashed his paycheck he sat in the restaurant and spoke of the changes in his life. "When I lived in Willowbrook, I could never do anything for myself. I was always inside and couldn't go out, like I do now."

His father, Hy Siegel, agreed. "Back then, Martin was nothing but a vegetable lying on a cot in front of the television." Today, Siegel said, his son has a good life.

Martin is moderately retarded. He has difficulty making associations and grasping concepts. His palsy makes eating and writing slow and laborious. In conversation, Martin is direct and has an excellent memory.

"Ask Martin anything," said his father, "the phone number of the house where he was born, birthdates of relatives. He'll remember it."

Life after Willowbrook

As did many families with mentally retarded children, the Siegels found caring for their son at home a strain on their emotions and finances. At 14, Siegel volunteered to be placed in Willowbrook, then considered a model institution. By the mid-1960s, conditions had deteriorated.

There's not much Siegel remembers about his 16 years in Buildings 5 and 10; it was an empty and deadening time.

"Willowbrook was like, mostly kids, and in those types of buildings where they're closed in all of the time. Kids were beat up. They ran all over and in the halls naked.

"The staff would use the same towels for more than one patient and so people would get rashes and

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boils all the time.

"I did nothing, just sat and watched TV in the lounge. I was very embarrassed to sit like that all the time."

Today, Siegel lives with 14 others in a three apartment suite in Rego Park, Queens, managed by the Young Adult Institute. He keeps up with his father, a Florida newspaperman, and his brother, a winery worker in New Jersey, with visits and telephone calls. He sees friends for dinner and religious holidays.

By the terms of the Willowbrook Consent Decree, Siegel should be living as much as possible as if he were not handicapped. He makes some choices about his daily life and exercises a modicum of responsibility and self-expression. At home, several social workers provide supervision and counseling.

Siegel has a bank account and handles his own spending money. Because of his slow pace and poor balance, counselors allow Siegel to leave home only with another person. He negotiates crowded sidewalks and crosses the street carefully. Siegel has spoken to groups of mental health professionals about his life in and out of institutions.

"Martin's very content in his group home; he has a full life," his father said. "The move out of Willowbrook was tremendous. It made a man out of him and gave him independence."

Parents of mentally retarded children often fear for their offspring in new situations. The old ward may have had its faults, but it was familiar and alternatives were limited. The first days of Siegel's independence cost him physically and strained his father emotionally.

"I almost went to court when he was first in the Queens home because they let him out on the street and he was always falling down," Hy Siegel recalled.

"But the counselors trained him how to do it. I give them a lot of credit. And I'm very proud of Martin."

Siegel grew into his freedom. Now, at 44, he looks forward to his next residences, a house in Flushing, Queens.

"Since I'm still young," he said with a smile, "I can have the chance to be more independent. I will be able to take the (public) bus, instead of going everywhere in the van like we do here. A counselor's going to go with us until we learn."

Siegel will continue living with other mentally handicapped adults. He doesn't seem to mind; he knows no alternative.

"It's better than Willowbrook," said Ronnie Cohen, a staff consultant for the court-appointed Special Master's office, which oversees state compliance with the consent decree. She met Siegel shortly after he left Willowbrook.

Other experts complain that the group homes



resemble small wards. Professor Wolf Wolfensburger of Syracuse University defined any residence where 12 or more unrelated people live as an institution. Both Cohen and one of his counselors say Siegel could live on his own, as do about 200 former Willowbrook patients. Both doubt he will.

"The powers that be have not adopted the goal of normalization; group homes still have 10 to 15 people," Cohen said, who has been both a caseworker and a supervisor in programs for former Willowbrook patients. "Many clients work in sheltered workshops — non-vocational settings contrary to the spirit of the Willowbrook settlement."

Siegel works at United Cerebral Palsy's Katz Rehabilitation Center in Jamaica, Queens. Here, 150 mentally handicapped men and women perform repetitive tasks for low wages.

Some fill bags with potpourri; others assemble tool kits. Siegel loads trays with sanitary hypodermic needle covers. The work is for outside companies and employees are paid on a piece basis, depending on their production. Wages are a fraction of what an able-bodied person would earn at the minimum wage.

Siegel loads needle covers into blue trays. He sits at a set of brown work tables with a dozen colleagues.

"Some week, usually I make up to \$14, or even \$16, \$17, or \$18," Siegel explained. Learning to handle even this amount, his job counselor Susan Feig said, is a new accomplishment for Siegel after growing up in an institution where he was fed, clothed and given a bed.

Siegel's earnings are his to spend. Rent, food and other costs are covered by Supplementary Security Assistance and other governmental aid.

Siegel is a veteran at this shop, and has seen some colleagues graduate to jobs as messengers, clerks and janitors. Both he and Feig doubted he could do other work.

"I like it there," Siegel said. "I couldn't move on because of my handicap. I can't travel too far." Feig

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concluded, citing Siegel's poor balance. She also said his work pace is too slow.

Ronnie Cohen disagreed. She has seen many like Siegel in regular jobs.

"Martin could function very easily in supported employment, say in a bank where certain tasks are repetitive," she said. "It's ridiculous how he's been ingrained with this idea that he can't get around."

The Willowbrook Consent Decree requires that Siegel receive six hours of structured activity daily. His job fulfills that requirement but it is not leading to greater independence. For seven years he has filled up trays or performed similar tasks far away from the real world.

"He's wasting his time there," Cohen sighed.

At home, there is progress. Mentally retarded clients are often assigned, as part of their therapy, goals for progress in basic skills as hygiene and self-reliance.

"I can't go out by myself," Siegel said one day as he walked down 57th Avenue in Queens. "I used to go out by myself, but it got too hectic and I became nervous. That's when they gave me this traveling goal." He stopped at a crosswalk.

"No, we're not going to make it; that light's going to turn red." Siegel jutted his chin up toward a car in the intersection. "Look at that car; it shouldn't be on the white lines." He proceeded at the signal.

"I have to pick up my speed, to get from one side to the other before the light turns green. I mean red."

"When I can't go out, I practice at home with cards on the floor. And I try to go from back to front, front to back, left to right, right to left."

Siegel gestured stiffly, his whole torso turning toward each of the four directions, and then with a hand held vertically, he traces his passage from one to the other.

Critics like Bernard Carabello, director of the Self-Advocacy Association of New York, call the use of goals contrived and belittling to clients. He was a patient at Willowbrook for 18 years until his discharge in 1972.

"Every resident in a group home has to have a goal plan," he explained in his office on lower Broadway.

"Is that normal? In my home or your home there's

no such thing as a goal plan. When you're free to make up a your own goals for yourself, that's normalization. Mine is getting my driver's license."

Ellen Ashton of the Office of Mental Retardation/Developmental Disabilities (OMRDD) disagreed. "You should set targets for behavioral change, and skill development," she said. "I doubt staff members would respond to the patient's needs without something written down. Without these formalities, there can be benign neglect."

One goal for Siegel, said his counselor at work, is to improve his table manners. "Sometimes he comes back from lunch and you can tell what's he's eaten," said Feig.

At home, the staff looks for self-discipline and good habits, such as checking with them when he goes out. Counselors try to protect their clients in the same way that the large institutions hid their wards from a supposedly hostile world. Siegel still is not getting to know that world.

Visitors are often quizzed by counselors about their purpose. Siegel talks with just one of his neighbors, a blind woman. Other tenants in the building know his apartment as "that transitional place."

Some responsibility is theirs; only the community can initiate new members, though there are barriers. A New York neighborhood of highrises may not offer the ideal setting for social integration. Siegel's lifestyle isolates him further.

He travels in a van, goes to a special Sunday school class and works in a sheltered workshop. Siegel lives, works and relaxes with other mentally retarded people. Rarely is he with non-handicapped people, other than staff, from whom he could learn how to live.

Within his world, Siegel strives for more independence.

"I try to do things for myself as much as possible. I started doing things for myself when I moved out of Willowbrook 15 years ago. I just started doing more, I guess. I'm trying to do more and more as I get older."

(This is the second in a series of five articles. Tomorrow: Isabelle Weiner.)