

Peoples & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

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**Monmouth
University
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Center**



CHRIS MILLER


PHOTO BY
REBECCA SHAVULSKY

GARY RUBIN

TELLING IT LIKE IT IS

by Maryann B. Hunsberger

Gary Rubin has strong feelings about... well just about everything. And, when it comes to the state's system of services for people with developmental disabilities, he comes by those honestly.



Rubin, a member of the New Jersey Council on Developmental Disabilities, has lived it.

He lived at home until he was 15. Moved into the Woods School of Langhorne PA— a residential treatment center for youth with developmental disabilities—in 1980.

In 1985, at 20, Rubin moved to North Princeton Developmental Center. That same year, although he hoped to live in the community, he was transferred to another developmental center—Johnstone Training and Research Center, located in Bordentown until it closed in 1992.

When Johnstone closed Rubin finally moved to a supervised apartment in Hillside, Union County, run by Community Access Unlimited (CAU).

In 1994, he graduated from the supervised apartment program and went into supported living, sharing an apartment with a roommate. Support staff was available initially for 15 hours a week. Those hours were steadily reduced as Rubin needed less of those services.

In 2004, he moved to an apartment in Plainfield. The following year, he began working as the building superintendent.

He lives alone in his own apartment. In his job, he is responsible for cleaning the building, making sure the rules are followed, and assuring that the tenants are happy.

Rubin talked about his life's path—what it meant for him, and what it means for others.

“The Woods School taught us independence. It was a pretty good place back then.

“When I ended up at Johnstone, I was paid piecework to do shrink wrapping. My money was put into an account and I got \$10 a week and a carton of cigarettes.

“Then they put me in housekeeping.

“I made people's beds, mopped and waxed the floors and cleaned the refrigerator and counters in the kitchen. I worked about six hours a day doing that. And then I'd go back to my room.

“Then I worked for the Burlington County Recycling Center, picking up newspapers and cardboard boxes at people's houses. I got a regular pay, which was put into an account for me. But I was only given a small allowance to spend.

“Johnstone was brutal. I was duped out of my money by other residents. If I didn't give someone a cigarette, they would hit me. I was beat up all the time. I was in the hospital with cuts and bruises when someone hit me over the head with a chair. I had to get stitches. Most of the staff would just let the fighting happen.

“There were six shower heads on the wall and we’d have to shower together. There were no doors on the bedroom. I locked my personal belongings in a metal locker and carried the key. If I left it open, my things would be stolen. That happened a few times. Some people figured out how to take the door off the hinges and steal my things. It took forever to get my things back. People were out for themselves, so it was hard to make relationships. I made friends with a few people, but the relationships rarely became close.

“The staff would wake us up at 6:30 every day. We had to walk to another building for meals. Bedtime was 9:30, even when I was out working all day. I’d get back from work to find my dinner on a tray. I’d eat it and be told to go to bed. The food wasn’t good and the coffee stunk. I couldn’t buy food for myself, except for some snacks at the canteen.

“I didn’t get to watch what I wanted to watch on TV. I’d go into the day room and it would already be on to something I didn’t want to watch. I would go to my room and take my radio out of the locker and listen to it to try to relax. I had a TV in my room, but there was no antenna, so the reception wasn’t clear.

“I felt so worthless. I didn’t feel that life was even worth living. I used to be treated like an animal behind a cage. I would get depressed from it. I always hoped I’d be able to get out because I knew that was my only hope to have a real life.

“It was much better in the supervised apartment. Since I didn’t have a job, I went to a partial day program where I would do activities during the day. It wasn’t my cup of tea, but it was better than the developmental center.

“I got to go grocery shopping at Food Town with my support staff and pick out my own food. I liked it a lot. I bought steaks, veal, chicken and ice cream. I would go back to my apartment and eat what I wanted.

“Since I learned to cook at the Woods School, I cooked my own meals. All the years in the developmental center, I never got to practice my

cooking skills, even though I enjoyed it. It was exciting to me to be able to prepare my own meals.

“I could watch what I wanted on TV. The staff took us to movies, to the mall, out to eat. My favorite activity then was going bowling. I had a good house manager, Beverly Arnold, and she let me go places on my own at times so I would learn to be independent. It was so thrilling to me.

“They helped me with my goals so I could eventually be on my own. I was more independent at that point. I came and went when I pleased.

“I love my job. It benefits me well. I can collect my own paycheck and not just get an allowance. It’s so much different from when I was at Johnstone and felt that I had no reason to live. I now have a computer and cable TV in my apartment. I had nothing like this at Johnstone, where it was so boring.

“I miss Sam Jenkins, my old roommate. We are like brothers. I still have problems that get me down, like breaking up with my girlfriend. I don’t really like the single life. I’m 44 years old and need

more stability in my life. I could get that from having a woman to share my life with. My goal is to get back with my girlfriend and live together. Still, I feel much better about myself now than when I lived at Johnstone. I feel like I have a reason to get up in the morning now.”

Rubin said if he could do it all over again and call the shots himself he would have gone from his parents’ home to his own apartment.

“I’d rather have left my parents’ nest, forget the residential treatment center, forget the developmental centers, and just go out on my own like other people. It sometimes bothers me that I didn’t get to have that experience.

“I know other people who went straight from their parents’ house to an apartment. They have no clue about what life was like in a developmental center. They take for granted that this is how life was for everyone. My ex-girlfriend lived with her parents until age 25 and went into an apartment. I really do wish I could have had it that way. But, that’s not how it was.

“I’d like to work for tougher laws to get employers to hire people with disabilities. We then need to work on wages.”



Gary Rubin in his apartment in Plainfield, NJ

“When I left Johnstone, I was put in partial care because they couldn’t find a job for me. People coming out of institutions should work, not loaf in the community. As a Council member, I’d like to find a way to make more competitive jobs available. People with disabilities get the cruddy jobs and are in workshops doing piecework. There aren’t enough in the workforce making competitive wages in factories, office buildings and other places of employment. I’d like to work for tougher laws to get employers to hire people with disabilities. We then need to work on wages.

“Some states, such as Maine, have no developmental centers. New Jersey should be one of those states. Every governor in our state has failed in doing this. The developmental centers are so expensive to keep open because they have to house and employ so many people. I hope the governor we have now will see that it’s a waste of money to keep the developmental centers open.

“We should especially be moving people into the community in this economy. Some very intelligent people who can think for themselves aren’t treated with respect or allowed to be independent because they are living in the developmental centers. They don’t belong there. I don’t want to see any people going through what I went through living in a developmental center. I want to see people living with dignity.”

Rubin, despite the difficult path, is setting an example for that. In addition to serving on the Council, he is vice president of the Statewide Self-Advocacy Network and chair of their local self-advocacy group. He is on the PADD (Protection and Advocacy for Persons with Developmental Disabilities) Advisory Board at Disability Rights, New Jersey, and serves on the Olmstead Committee to help facilitate people moving from New Jersey’s developmental centers into the community. For many years, he was part of CAU’s self-advocacy group, Helping Hands. **P&F**



MYRTA ROSA

Ready and Waiting

by Maryann B. Hunsberger

For Myrta Rosa, her time living at Woodbridge Developmental Center helped her at a time of crisis.

But that crisis—the death of her parents—has long past. And she is ready and waiting to get back into a home of her own in the community.

Rosa moved into Woodbridge in October 1998. “I came here to try to get better. I get good care here.”

Rosa had lived at home with her parents and her sister Norma up until that point. She attended school at the CP Center in Edison. She is fluently bilingual. She learned English in school and acted as an interpreter when Spanish speaking people came to visit the school.

After graduation, Rosa worked at a workshop in East Brunswick for 10 years. A supervisor realized she could work in competitive employment and helped her schedule an interview at the Shop Rite in Perth Amboy. She was hired to put items where they belonged and to help the cashiers with bagging. She did this work for ten years.

“It was like a promotion to go from the workshop to competitive industry.”

As the years went on, her parents became disabled from complications of diabetes. They lost their sight and were on dialysis. Rosa’s parents didn’t want to go into a nursing home, so she and her sister cared for them for more than five years. After her parents died within a few years of each other, Rosa moved into her sister’s apartment, but she was depressed.

“I wasn’t myself. I had no energy.”

She came to Woodbridge to try to turn things around. After 11 years she’s more than ready to move on.

“I like the aides who work here and who take me on field trips. Most of my friends are staff members, since they are more on my level because they are verbal. Years ago, we took overnight trips to places like Atlantic City and Wildwood and I loved going in the pool at the shore. Lately we only do day trips, such as going bowling and out to eat.

“But I enjoy it most when my sister Norma picks me up and we go shopping or hang out at her place in Perth Amboy.”

Rosa works two jobs on the grounds at Woodbridge. She shreds papers in their workshop, which is on the ground floor of the hospital building. She also helps manage a boutique. A bank is

in the same building that houses the boutique, so Rosa picks up her paychecks there.

“I get paid for both jobs. I like the boutique better because I get to meet people. I’m a friendly person, a social being who likes to socialize a lot. Opening a boutique was my idea and I’ve been working there for seven years.”

Rosa was the president of the self-advocacy group at Community Access Unlimited (CAU). She did secretarial work, and learned computer and keyboarding skills.

She now volunteers with the New Jersey State-wide Self-Advocacy Project and the Self-Advocacy Network. She chaired their local council until recently.

For the past year-and-a-half Rosa has been a member of the New Jersey Council on Developmental Disabilities. She became familiar with the Council through its Partners in Policymaking leadership training project.

“I attended monthly weekend seminars in Trenton. Each weekend that I went, I saw that I could

do more things for myself. That gave me confidence that I’d be able to live in the community.

“I’ve been at Woodbridge for 11 years, and I was scared to leave. I like to be active and was afraid I might end up sitting in an apartment all day. I was also afraid of how people would react to me because I have a disability. I wanted to take time to research what I would do on the outside. Attending PIP was part of that research.

“The way the parents there treated me made me feel more confident that the community would receive me well. Everybody seemed to love me. I lost a lot of my fear when I attended PIP. It made me realize that I am back to the level of functioning where I was before my parents died, so I am ready to leave here and live in the community. I spoke at the graduation ceremony and people were in tears. I talked about how I loved PIP and the people I met.”

As a more experienced advocate for herself and others, Rosa has attended conferences in Indiana, California and New York.



Myrta Rosa works at the store in Woodbridge Developmental Center. Here she works the cash register.

“It’s good to see other parts of the world. One year, I did a presentation called ‘Don’t Let Your Disability Hold You Back.’ I feel that title describes me because I try hard to do everything. Adults with disabilities need to live as normal a life as anyone else. Having a disability doesn’t mean we can’t help others, and I’ve had the opportunity to help a lot of people. I even advocated for the automatic doors on the buildings at Woodbridge to make it easier for people.”

After her graduation, Rosa approached CAU and told them she wanted to move into the community. Trace Baxter, assistant director of training for Caregivers of New Jersey serves as Rosa’s support coordinator. Baxter has been helping Rosa prepare for her move.

Rosa will still work at the boutique at Woodbridge after she moves into the community, as well as having an outside part-time job.

“They wouldn’t have anyone to run the shop without me, so I’ll stay on at the boutique.”

A smile appeared on Rosa’s face each time the new home was mentioned.

“I’m excited to move. I’m most excited about having more freedom. It will be nice to not have to ask permission and depend on staff to take a walk in the nice weather. I’ll be able to just take a walk when I feel like it.”

Rosa was especially excited about the prospect of finally having her own bedroom. She now lacks privacy, since she has to share a bedroom with two other women. Our photographer couldn’t take pictures of her room because one of her roommates was asleep.

“She might hit one of us if she wakes up and gets mad. She socked me before.”

Rosa can hardly contain her enthusiasm about the idea of having more privacy and some solitude. It’s easy to understand this, since we couldn’t find a quiet place to do the interview. We had to settle on sitting in the tiny lobby of cottage 11, while people came in and out of the door.

Myrta Rose walks from work at the store to her cottage at Woodbridge Developmental Center.



“Having a disability doesn’t mean we can’t help others, and I’ve had the opportunity to help a lot of people.”

“I’ll have my own TV in my bedroom and I’ll watch whatever I want without people talking. I can’t even hear the TV when I try to watch here. I really look forward to choosing my own meals. I don’t like a lot of the meals here, so I just eat bread and jelly a lot. I just have to bear with it until I get out. I’ll figure out how to decorate my bedroom after I get there.”

Rosa is excited about joining a gym, cooking healthy meals and losing weight once she moves to the community. She hopes to move within two months. “A lot of paperwork needs to be done. I can’t wait to move.” **P&F**

(Ed note: At last report it seemed that Rosa may be moving to her own place as this issue hits the streets.)