

Chapter Eight Marie's Supported Employment

Our UAF constantly shared its most effective practices in social care and support for people with developmental disabilities. STP employees travelled throughout Oregon and around the country, documenting best practices and offering technical assistance. As I traveled around the country, I met wonderful people. This is how I met Marie in a small town on Georgia's coast.

Marie was a young woman in her twenties. Everyday she was transported to a sheltered workshop that trained people with disabilities to perform work tasks. When I met the management staff of this program, they told me that Marie was a person that they "could do little with." Marie was unresponsive, they reported. Over the years, they found that it was best to leave Marie alone. I felt that I was in an awkward position. I was trapped in the role of the expert who was expected to produce a change in Marie and this in fact is exactly what I had chosen to do—be an expert who produced change. I had put myself in this position by choosing to consult with programs. Typically, in such circumstances, I would try to raise a reaction from the person with disabilities and then reinforce new, appropriate behavior. That wasn't going to happen this time. Not with Marie.

It was around 10:00 a.m. when I first met Marie sitting in the production area of the workshop. The design of the desk she was sitting at immediately caught my attention. It looked like something out of Puritanical America. The chair was against a wall, and the desktop encircled Marie's body. While not discomforting Marie, the desk did restrain her. It kept her

seated. One of Marie's problems was that she would stand up and run for the closest door screaming and creating pandemonium in the shop. My attention shifted from the chair to Marie herself. She was a small, thin African American woman with short hair. She had no teeth and her eyes would never look into mine. They seemed to remain unfocused while constantly scanning the production room. Marie was holding a Rubik's cube close to her right eye. She was not trying to solve the puzzle, but instead slowly rotated the cube close to her right eye. Marie did this hour after hour, day after day, month after month.

I felt something happen inside me when I was with Marie. For years, I had met people like her, and once I commanded their attention, I would begin my training or teaching. This is what the professional staff supporting Marie rightfully expected me to do. Instead, when I sat down next to Marie and said hello, she just quietly spun the cube. I waited and tried again; nothing happened. And again, still nothing, and again and again. Nothing. But something *was* happening inside me. Although I was in an environment telling me, "Don't just sit there, do something!" from somewhere inside me came another voice, "Don't just do something, sit here and be present!"

After an hour and a half or so, two staff members came over and told me that it was time for Marie's break. The four of us went outside. The sun was warm and bright as I noticed that Marie's arms were dotted with round scars. I must have been staring because one of the staff said, "Those are cigarette burns. The folks at Marie's home used to put their cigarettes out on her arms." Looking at her burns and again at her toothless mouth I thought, "What have they done to Marie?" As I spoke with staff members, Marie strolled through the cyclone fenced play yard. She seemed happy in the spring sun. Still holding her Rubik's cube up to her eye, she

seemed to float about the play yard. Even with her awkward gait and physical scars, I felt I was watching a happy young woman enjoying the sun and fresh air.

After lunch (which entailed a staff person cutting and feeding Marie her food), we went back to her desk. She resumed her position, and I resumed mine. There was absolutely no sign that Marie had acknowledged my presence. I felt myself beginning to share Marie's view of work, at least, her perspective of the rest of the workshop. When sitting side by side with Marie, this shared view became more important to me than making Marie do anything. In the moment, I was lost in this thought and didn't see the staff person coming. "Marie, put that block down and shake hands with Dennis!" The staff evidently felt that something should happen and it did. With one move, Marie knocked over her desk and ran screaming for the door. All was chaos. Other workshop clients were yelling, Marie was yelling, and the staff were yelling at Marie to sit down. Marie ran, staff ran after her, and I ran after them all. The staff caught up with Marie outside in the play yard. They escorted her back to her desk. I let them know that I didn't expect Marie to do anything. I was happy with what was going on. For the next hour Marie and I sat side by side as I listened to others with and without disabilities complain about her and call her names. A new perspective came to me: this had happened many times before. Socially, Marie was the least-valued person in the program. She took from others (demanding their attention and support) and gave nothing in return while he sat silently spinning her cube. I could feel Marie's sweetness but could not feel any aggression or anger from her. I listened to the complaints. I thought about my consultant role: "What am I doing to Marie?"

Hours passed and nothing changed. I sat quietly next to Marie. She quietly spun the cube. I guess I was expecting her to answer my original *hello* even though so many hours had passed. Then it was time for Marie to go home. By that time I was pretty sure that I had become the laughing stock of the program. The respect for the consultant, The Expert, was replaced with a contempt that hung thick in the air. I let them down. I hadn't even tried. Marie just sat, quietly spinning her cube.

Everyone got up to leave. Walking to the lunch room, I was very confused. What had been accomplished that day? I had followed a hunch that Marie would initiate a relationship with me. But why should she? My stubbornness over not wanting to train Marie had prevailed. *It's true*, I thought as I walked through the lunch room in a crowd of people with disabilities, *I'm simply tired of trying to control people. All that I have done is to disrupt all of these good folks' time.*

I felt something touch me from behind. Something had brushed up against my arm. I thought nothing of it in the crowded lunch room. No, there it was again. Something solid was being pushed against my arm and hand. I turned around. It was Marie. She was holding the Rubik's cube out toward me. She was offering me her cube! I took the cube with my right hand and held Marie's hand with my left. Spinning the cube, I stood staring at Marie. Still, she wouldn't look into my eyes. For fifteen or twenty minutes, we stood holding hands while I spun the cube. I felt honored by Marie's trust and the privilege to have the cube. In fact, it probably was one of the greatest honors I had as a professional. Then it was time for Marie to get on the bus for home. I offered the cube to her. She took it and walked away from me and I thought, *What has Marie done to me?*

Later, I realized that she had been supporting my employment. Moreover, she showed me that supported employment, like the support networks I had been studying, was mutual. We are all clients, and we are all providers of support. That sunny spring day in Georgia, Marie gave more to me than I to her.

Liberation occurs whenever we as individually or collective are free to reflect upon how we do what we do. Marie and I ended my profession in disability services but not the liberation movement. In the short interaction, the feelings were so intense, the distinction of “disability” disappeared. I could no longer accept a salary in supported employment while folk’s like Marie were not paid. I thought that businesses joined us expanding workplace cultures of living well together they would bring about networks of conversations that cared for and supported people.

The practice of the scientist-practitioner had brought me freedom. As long as the wellbeing of those we cared for constantly improved I was free to innovate in a recursive cycle of reflections upon how do we do what we do when we live well together. I was inside the network of conversations and found comfort and care from Marie and now could see that the network of conversations were forming in a constant flow of conversations that conserved the reflections, including Marie’s.