

Consumer Voice--Not Yet Consumer Choice: A Personal Experience

by

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Introduction

My name is Moe Armstrong and I am with the Peer Educator's Project and also Director of Consumers and Family Affairs for Vinfen Corporation. It is really interesting when universities, rather than just continuously trying to find which neurons are causing our mental illness, do programmatic research.

Mental Illness as a Health, Not a Social Problem

Is managed care working? It is working as well and better than I ever really dreamed possible. It is working with the amount of money funded in our system and I think that is the real challenge at hand. Those of us with psychiatric conditions are still seen as social problems and not as health concerns. As long as this is the perception, our system will be under funded and under staffed. The reasons you don't see people with mental retardation lost and alone and in jail, homeless, and wandering the streets is that their system has money and coverage and our system does not. Someday we are going to have to quit punishing those of us that have mental illness and see us as people in need who need some kind of care. I couldn't imagine talking about cancer and people talking about getting rid of chemotherapy and radiation for cancer patients. But in mental health, we are always talking about when to cut, how much to cut, and where to cut, and we are probably one of the few health areas that act like that.

Co-Occurring Disorders

I can't thank you enough for talking about co-occurring disorders. I think that most of us (I have schizophrenia and I was also homeless), never asked to be mentally ill or to be addicted to drugs and alcohol. It happened from my time on the streets of America, getting involved with people who got me high and loaded. Not only did I then have mental illness, I was also addicted. We have to talk about and understand addictions, as well as mental illness and where this comes from.

Consumer Voice

I want to talk with you about consumer voice and not yet consumer choice. Today most of us with mental illness and psychiatric conditions are on boards and panels and everything else (I am one of those people). But what has been difficult if not impossible is to have people with psychiatric conditions involved in the day to day programs and administration of our own mental health programs. Mental health is like blind services or deaf services a hundred years ago. You never saw people who were blind and you never saw people who were deaf working in that system of care. Those of us with mental illness or psychiatric conditions are going to be the future work force of

mental health. If we had spent all of our time, money, and effort developing the people in our programs to be direct care service workers to work in our own mental health system, then we would have a group of people, who would not be working in McDonald's, Wendy's and all the other places that we farm people out to. We would have a mental health system that looks like none of the mental health systems that I could ever imagine in the history of mental health.

I compare it to women's organizations. Suppose you are a person like me who has a mental illness and you walk into the mental health system and there are not any of us working there. It is like walking into a women's organization and there are no women working in it. People are very well meaning. I am grateful for the care I have gotten over the past thirty-five years. But we need to do a better job of training, developing, and recruiting people who have psychiatric conditions to work in our own mental health system. When those of us with psychiatric conditions are working in our own system on the floor with other people and setting up support meetings, because of our own personal experience or interactions, we can bring stability to our own system of care. We have not done a very good job of that.

Future Improvements

The future will see three new components that we really have not put into place. First, as much as people have talked about and promoted Act teams and even intense case management, I prefer to call these numerous people, with a variety of homemaking skills, friendly, outreach workers. We need people who are going in and seeing that the apartment is cleaned up, that there is food in the refrigerator, that people have something to eat, and that people are getting to the appointments they need to get to. We do not need to spend a fortune on MSWs and psychiatrists running around on Act teams and even intense case management. We need many people working with those of us who have psychiatric conditions. I know my mental illness is very disorienting. I need somebody to come over to my house to help me get straightened up because I'm collecting data, paper, articles, interviews, anything I can get my hands on; I need somebody to help me sort through that. I keep the place fairly clean. I'm still a little scruffy around the edge. Maybe I could do with a wardrobe change. I need somebody to come over to the house and help me take care of all these little adjustments so that I'm not overwhelmed by the personal stuff. Many other people who have psychiatric conditions need that same thing and to learn how to eat appropriately, have some food in the refrigerator, make sure that they are eating well, and getting to where they need to go.

The second thing that we need that is not funded is more crisis stabilization units and residential crisis units and mobile outreach teams to keep people in housing and not lose housing. Keeping people housed is one of our primary jobs. The best way to do that is crisis residential units, crisis stabilization units, and mobile crisis teams that are responsive and on call, with no long-term waits. When somebody calls, take them in, turn them around, and get them back out into their apartments so that they don't lose their housing.

The third thing we need are welcoming non-ideological day programs. These are day programs that when you or I or whoever has a major psychiatric condition walks in the door, we are actually made to feel like its our program, we're welcomed, and there are not hoops and barriers and waiting lists and all the things that are out there right now. This is a great chance for those of us who have mental illness and psychiatric conditions to work in our system. We are going to have to become a lot more attuned with people, what I call the four F's: fun, fresh, flexible, and forgiving. Day programs seem to fit that mold. We can bring a higher success of recovery and stability to many people. We can make the mental health system a showcase of human service care.

We've Got to Believe

I've seen ideas come and go. When I first came into the mental health system, everybody got involuntary electroshock. The mental health system has come a long way today. None of use ever asked to be mentally ill. I have never met a person who wanted to be addicted. All I have ever encountered is people trying to come out from under addictions and mental illness, and struggling to find the way. Our job is to provide that support and care.

We know what to do. We've got to do it. More than anything, we've got to believe in ourselves, and we've got to believe in our system. We've got to see when we have an opportunity. Managed care could be done better, but I could be doing better with my own life and recovery also. Nobody is perfect. No system is perfect. We've got to take that message that our system works, that we can do better if we have the funding, and that mental health and substance abuse are no fault, no blame conditions. When those of us with mental illness start to get sane, stable, safe, and sober, we have a chance to develop our highest potential in life.

For me, mental illness never went away. For me, every night I am haunted by will this be the night that I fall apart? Will this be the night that I start to hear those sounds? Will this be the night that I don't make it? I call it that I'm having an unbeautiful mind episode. We can do it folks, but we got to believe in ourselves. We are going to have to take a message, an unapologetic message that what we're dealing with is a health concern and not a social problem, and it is called mental illness.