Still fighting: Interview with Judi Chamberlin

written by Betty Reid Mandell | January 12, 2010

JUDI CHAMBERLIN IS ONE OF THE FOUNDERS of the mental patients' liberation movement. In 1988, she wrote *On Our Own*, a book about her own experience with depression 43 years ago, when she was hospitalized against her will. That book became a kind of bible for the mental patients' liberation movement. Now the 64-year-old activist is dying of chronic obstructive pulmonary disease, an incurable lung disorder. Late last year she stopped hospitalizations and instead opted for home hospice care.

An article in the *Boston Globe*[1] talked about Judi's fight with her insurance company because they had discontinued coverage for hospice care. The article said that her insurance company recently told her that she had "used up" her hospice coverage, which was limited to $5,000. They told her that she could file an appeal, which she did. She said, "It seems so counterintuitive when you think about what the insurance company paid for me in 2008. They paid thousands of dollars for me to be in the hospital all the time. Hospice care will cost my insurance company much less." The representative from the insurance company, United Healthcare, offered to help her with the paperwork for an appeal. He said, "I wish there was a clearer process. Benefits do get used up."*

Her hospice (Visiting Nurse Association), has assured her that they won't abandon her, but she worries that her daughter and her partner may be saddled with thousands of dollars in unreimbursed hospice bills when she is gone. She said, "My mother had a gruesome hospital death" from breast cancer. She described her mother's struggle to breathe, miserable and surrounded by machines as specialists hovered over her, suctioning fluid from her lungs in the last hours of life. That experience persuaded her father to choose home hospice care six years ago as he rapidly declined from congestive heart failure. "He wanted to die in his bed. He was relaxed and at peace."

Judi said that in choosing to follow her father's footsteps, she never envisioned that her hospice path would include such a battle. Neither did her primary care provider.

The administrator at her physician's office, Arlington Family Practice, helped her with her appeal. She said, "I have never had an insurance company call me and say a patient has exhausted her hospice. I was devastated when they called me about her case. You mean this woman can't have hospice because she didn't die fast enough?"

Judi said, "Although I apparently haven't died fast enough, I wrote in the "reason for request" section of the appeal, "I do have a terminal illness and will need some method of care." And she added, "Since I become eligible for Medicare in October 2009, the plan's obligations would end then (providing I am still alive.)"

BRM: I first interviewed Judi in 1993 for my human service text.[2] Here is what she said in that interview:

JC: I have spoken at conferences all over the nation and the world. The best conferences have been those to which users of the mental health system are invited. A 1988 conference in England, for example, called "Common Concerns," was attended by an equal number of workers and users. In the United States, the National Institute of Mental Health sponsored a pioneering set of dialogues in Florida. Users and service providers explored issues together. The National Conference on Mental Health Statistics contacted me and asked me to participate in the first conference involving users as well as researchers. This surprised me, because people don't usually seek out the opinions of mental

patients. They think, "If you're mentally ill, what do you know?" Whatever a person has to say is suspect.

When students learn about the mental health system, they only hear the views of the professionals. They seldom empathize with the mentally ill or try to understand how it feels to be on the receiving end. If they want to have an honest dialogue with the mentally ill and ex-patients, service providers have to be prepared to face their anger and mistrust. People who use services have been treated in paternalistic and controlling ways, and this understandably has made them angry.

The attitudes of service providers have caused a split between the Alliance for the Mentally Ill (AMI), a support group for relatives and friends of mentally ill people, and the Mental Patients' Liberation Front (MPLF). Parents in the AMI argue, "We love our sons and daughters and want them to get help. We may trick them if we have to, whether they say they want it or not." The patient may not want to take drugs, but relatives often think they should and complain that patients don't take their medications. (Research has shown that a high percentage of all drugs, not just psychotropics, are not taken according to the doctor's prescription.)

I have tried to promote dialogue between AMI and MPLF. Ex-patients and families have one thing in common: They didn't choose to be in the system. Professionals choose to be there. It is important to recognize that families have a valid perspective.

Some people accuse the MPLF of being totally opposed to drugs, but I believe in choice. Patients need to have all the facts, which are often kept from them. The professionals sometimes feel that if they give patients information, they only scare them. I tried drugs but didn't find one that helped me. For me, drugs didn't work, but I wouldn't tell anyone else what to do.

Research on phenothiazines shows what happens when patients don't have all the information. Although it is now well known that phenothiazines cause tardive dyskinesia (involuntary tics), not until recently did it come to light that they also cause tardive dementia, a loss of brain function. Patients can deteriorate mentally when they take the drugs. Professionals had not realized this earlier because they assumed that mental patients were deteriorating because of their illness.

The average doctor knows very little about drugs, often only what the advertisers say. Journals are filled with drug ads, and at medical conferences drug salespeople are all over the place. The field is controlled by profitable pharmaceutical companies. For example, there are two identical drugs for a heart condition, one generic and one with a trade name. The trade drug is six times as expensive as the generic, and that is the one that doctors prescribe most. A tranquilizer called clozapine used to cost $9,000 a year but has come down in price because of so many complaints. It doesn't cause tardive dyskinesia, as do all of the phenothiazines, but it can kill users if not correctly monitored.

Almost everyone in the psychiatric field has gone into diagnosing and drugs. Most of the professionals doing talking therapy are psychologists and social workers. There is very little clinical psychological training for doctors anymore, except for long, arduous psychoanalytic training. The conventional psychiatric wisdom is that you can't talk with psychotics. Most psychiatrists, and the AMI, believe that mental illness is primarily biological and can be controlled or cured only with drugs. The Alliance quotes statistics by the World Health Organization, which indicate that schizophrenia affects 1 percent of the human population worldwide. The AMI denies that stress or trauma causes mental illness, yet there is a good deal of research that challenges this belief. Researchers have tracked unemployment and mental hospital admissions showing that mental illness rises with unemployment. Research about women in mental hospitals indicates that as many as 50 to 80 percent have been sexually abused.

Interestingly, the rate of recovery of mental patients is higher in third-world countries. I believe that is because they have stronger family and community ties. Also, traditional healers, who would be used more in third-world countries, sit with the patient, sometimes for days. In Africa, for example, a native healer spends several days observing the patient. That presence sets up a powerful therapeutic alliance. The healer does not think that it is important to ask questions but that it is important just to be there.

A few psychiatrists still believe in talk therapy and are cautious about using drugs. One of the best is Peter Breggin, who wrote an excellent book called *Toxic Psychiatry* (1991). Another important book is *Community Mental Health: Principles and Practice*, by Loren Mosher and Lorenzo Berti (1989), which proposes a blueprint for a comprehensive community mental health system. The authors maintain that before taking drugs, people should have a chance to get real community support. Once people start on drugs, they are likely to stay on them and have a hard time getting off. Mosher and Berti believe that a society can run mental health systems without hospitalizing anyone.

Drugs are used extensively all over the world. Most of the alternative mental health programs of the 1960s and 1970s have died, although a few proposals have been made for new ones. Although there has been a lot of talk about the innovative programs in Italy, where there are no long-term institutions, Italian practitioners still rely on drugs. Some community cooperatives have been set up there (not sheltered workshops, but co-ops actually owned and run by ex-patients).

[June 2009: I interviewed Judi for the second time at her home.]

BRM: Tell me about hospice care.

JC: They are on call 24/7 by phone. They provide my medication. A nurse visits twice a week, and a social worker visits. There are two volunteers who visit regularly. Hospice aims to help a person make the last part of life as good as possible. The hospital treats symptoms, and is not concerned with the quality of life. I pay for acupuncture, Reiki, and massage at home myself. The hospice organization that I had before included Reiki. It is very relaxing and helps me sleep.

I'm not religious, but a chaplain visits and she and I have good conversations. Lots of thoughts go through my head about dying. There are practical things to take care of, as well as philosophical thoughts. A lot of people don't want to talk about death and dying. A lot of people don't go into hospice until the last week of life. That is better than not going, but it would be better to go in earlier to work on issues of closure. A lot of families need to come to closure.

People's relatives and friends often have a memorial service after a person dies. I have thought about that a lot, and think I would rather have the memorial service before I die so I can enjoy it. That's one big project that I am planning. We will need to get a large hall because about 100 people will come. I will call it a "celebration of life." If I die before it takes place, people can still have it.

BRM: Are you the founder of the mental patients' liberation front?

JC: I'm one of the founders. During the 60s and 70s, there were people in different cities — San Francisco, Boston — and there were people in Europe — England, Sweden, Japan. It bubbled up all over, along with other liberation movements. I think of it as like mushrooms sprouting up all over. Liberation was in the air. The groups that formed did different things. Some offered services, some worked to change legislation, some were more militant than others. There are still some groups around, but the militancy died down. We have been talking about reviving the militancy and it's beginning to happen. Alternative services are important, but there are things wrong with the system

that need to be changed.

BRM: How have things changed with mental patients' liberation since I interviewed you in 1993? Do you think people are more respectful of the opinions of the mentally ill, and have more empathy now? Are service providers less patronizing? Is there less stigma about mental illness? What changes have you seen?

JC: The stigma has lessened somewhat, but it is still very strong. It's not politically correct to make jokes about blacks or gays, but it still considered o.k. to joke about the mentally ill. People still assume that the mentally ill are violent.

However, there is more recognition that ex-patients have a role to play and some expertise. There are a lot of different support groups. Younger people are doing a lot of organizing on the internet. One group is www.mindfreedom.org. David Oaks is the executive director. He is based in Eugene, Oregon. He is working with the World Health Organization and the World Psychiatric Association. Another is the National Empowerment Center. There a lot of other in-person and on-line support groups. People are reaching out and finding people who have had similar experiences. So many people say, "I'm so alone." They feel cast out of the human race. It's a very scary feeling. When you link up with other people with similar problems and find out you're not alone, it is very reassuring.

The mental health establishment believes in medication. Professionals say, "You have to take your medication." For us, it's about what works. We believe that people should have the opportunity to lead ordinary lives, with needed supports. The issue is not whether you take medication or not. The issue is whether you're leading the kind of life you want. The journalist Robert Whitaker wrote the book *Mad in America*. He investigated the statistics of mental illness and found that the number of people diagnosed with mental illness keeps going up and the number of people on disability keeps going up, despite all the claims that drug companies make about medication. A typical anti-psychotic drug causes severe obesity — 100 pounds or more — and diabetes. But it is very profitable for drug companies. The power of drug companies keeps growing. Lots of doctors are getting huge amounts of money from drug companies, and lying about it. They get hundreds of thousands of dollars. Drug companies and doctors have everyone convinced that the problem is biochemical, but we see it as psychosocial. Poverty is a factor. Life on SSI (Supplemental Security Income) is pretty miserable because the grant is so low. There is a "Ticket to Work" option to encourage people to try working, and to enable them to return to SSI if it doesn't work out. But people are wary of trying that because they know how hard it is to get on SSI, and they fear that they would be left with nothing if they were denied SSI.

A lot of people are scared, especially about health care. There have been deep cuts on programs that help people stay in the community. Mentally ill people are being sent to jail, and to emergency rooms. This country is spending billions to bail out banks and corporations. It is spending money for welfare for the rich, not for supports for the poor.

There are new problems surfacing with teenagers and kids. A new generation of kids has been on some drug since grade school. Their issues are medication at home and at school. They are very angry. They are often diagnosed as bipolar. Psychiatrists are even prescribing anti-psychotics for little children, as young as 2 years old. A little girl who was taking anti-psychotics died under still-undetermined circumstances, but it is clear drugs played a role.

Ours is a strength-based model. It is important to teach people skills, and train people to be advocates and mentors. That changes how people think about themselves. Instead of making sickness his identity and saying, "I'm Joe, I'm schizophrenic," he can see himself as somebody with something to give others. We aim to put people in positions of power over their own lives. When

people feel powerless, they are overwhelmed. When everyone is making decisions for them, it is not surprising that they don't have good outcomes.

BRM: What do you think about deinstitutionalization, that closed public hospitals and sent patients into the community?

JC: We no longer have many long-staying facilities. We have a lot of group homes, which are little institutions. There is a lot of homelessness among the mentally ill. People need their own homes, rather than an institution. We are looking at what kinds of supports people need. One support that people need is housing. There is no way to stabilize your life if you don't have a place to live. The Housing First program seems promising. The philosophy is to find an apartment for people first, and then offer social service supports that they need to stay in the home, on a voluntary basis.

BRM: Electroshock seems to be used more than before. What do you think of it?

JC: Psychiatrists' PR efforts during the 1970s and 1980s misled the government, the public, and the media into believing that shock therapy was safe, and if it caused memory loss at all, the loss was short-term. Yet there is a lot of evidence that memory loss is sometimes massive, and memory may not return. Linda Andre has written a book, *Doctors of Deception*, a history of electroshock in the U.S. She says that electroshock treatment caused massive memory loss and ruined her life. Marilyn Rice told of how after a series of shock treatments, she returned to her professional job and when she went to office to resume her job, she couldn't remember a thing about what to do. She became a crusader against shock treatment, and Linda Andre has succeeded her in this mission.

BRM: More women (proportionately) than men suffer depression. Do you have any thoughts about why this is?

JC: Women are more likely to be diagnosed with depression. Men are more likely to be diagnosed with schizophrenia or rage kinds of disorders, and are more likely to end up in the criminal justice system. The country's military culture encourages macho aggression, and discourages men from talking about their problems. Women are more socialized to talk about their problems. We have enormous numbers of soldiers returning from war with PTSD who are reluctant to ask for help. Since there is no draft in this war, poor people are taking the burden. Middle class veterans had the GI bill after WWII, but that only worked for white people.

BRM: Does the mental health system treat gays and lesbians differently?

JC: Until fairly recently, homosexuality was considered a disorder that needed treatment. Lots of parents send their kids to boot camps because of their fears about their kids becoming a homosexual.

BRM: If any of our readers would like to contact you, could they e-mail you?

JC: Yes, I would be glad to have them contact me with email.

BRM: I have looked at your blog. I notice that you had a craving for pea soup. Would you like me to make you some?

JC: Actually, other people have made some and we still have a big pot of it. What I really crave is baking powder biscuits. I read about some terrific southern biscuits and I went on line to see if I could buy some, but I couldn't find them.

BRM: I'll try my hand at making some, and I'll bring some fresh strawberries so you can make

strawberry shortcake. Should I also bring whipped cream, or is that too fattening?

JC: Bring the whipped cream. I'm dying, so I might as well eat what I want.

Footnotes

* Later, the appeal was successful.

1. Kay Lazar, "Advocate for others fights to die at home," *Boston Globe*, May 22, 2009.

2. Betty Reid Mandell and Barbara Schram, *Introduction to Human Services: Policy and Practice*, 7th ed. Boston: Allyn & Bacon, 2008, pp. 47-51.