



## The Nicest Warrior I Know

*A conversation with Judi*

**Kenneth Braitman**

Judi Chamberlin, who has been at the center of the national recovery and empowerment movement since in 1971, sounded in excellent spirits Dec. 19, when she spoke to me from her home in Arlington, Mass., where she is receiving Hospice Care. In fact, she sounded ready to work in the movement for another 37 years if she could. “I plan to live until spring, unless I run out of energy,” Judi said.

I’d asked to interview her in connection with a book I’m writing on the history of the recovery and empowerment movement, which could not be written without Judi’s contribution. She said she always thought the story of the movement should be told, and was glad someone was working on it. And she said she definitely wanted to be included.

What struck me most, which we came back to many times in different words, is that Judi does not believe the mental health system is much better, or even much changed, since she went to her first meeting of the of the Mental Patients Liberation Project (MPLP) in 1971, soon after her only involuntary hospitalization in New York State.

I found It sad that a person in Hospice care should sum up nearly 40 years, a lifetime, of work that way, but she did not sound at all sad, morbid, or bitter in any way. She just said, “The work won’t be finished as long as there is forced medication, involuntary hospitalization and electro-shock, and conditional discharge.”

She was absolute about forced medicine and hospitalization. “The criminal justice system should deal with the people who are really dangerous. People who are just bothersome, annoying, or who make you want to tear your hair out, should have someplace to go for support, not coercion. We should have crisis respite centers.” Judi said.

“I’m not against medication when it’s presented as one of many options and the person has the right to choose. If you think medicine helps you, you should take it. But people are told by mental health professionals and their families, [who listen to mental health professionals] that there is no choice, and if you don’t take medicine, you’re stupid, stubborn, or non-compliant.”

And if you stop your medicine, and don’t comply with your conditional discharge, you go straight back to the hospital, often in handcuffs, in a police cruiser, I said, finishing her thought.

“MPLP was a political group, patterned after the civil rights movement, Women’s Liberation and Gay Liberation, which were just coming together,” Judi said. “I always viewed it as a civil rights movement, my civil rights movement, though I was also involved with women’s liberation.”





“Personal support was peripheral, but it quickly developed a personal support element,” she said. “We didn’t use the word ‘recovery’ at the time. I’m not sure when that term came into use. But if someone in our meeting got upset or became disruptive, one of us would ask if he wanted to come outside, take a walk, and talk about it. We found that mutual, supportive listening, without judging or assessing or diagnosing, helped people more than talking to a professional, with that unequal sense of ‘you’re weak and I’m powerful; I know more than you do about what you feel and what you need.”

Ever since, Judi has spread the idea that activism makes for a better support group, and mutual support makes activist groups more effective.

She said she never chose mental health activism as a career. She wrote a book, people paid her to speak to them, and she kept finding more ways to get paid for what she would become her living as well as her life’s work. Her most recent affiliations were with the National Empowerment Center, a recovery and empowerment think tank run by ex-patients, and Boston University’s Center for Psychiatric Rehabilitation, another think tank run by academic researchers.

Between 1966, and her involuntary commitment in 1971 (she was 21), Judi had several voluntary admissions, but since the involuntary commitment, she has always stayed out of hospitals.

“I’d get depressed, I’d isolate, become suicidal, but I would hold on any way I could, did whatever helped me, till I came out the other end” she said, rather than go back to a hospital, or to a mental health professional, who would send her back to the hospital.

The involuntary commitment to a state hospital was the transformational event in her life, she said. “The fundamental injustice! They said I had a brain disease, so I couldn’t possibly know what I needed, and could not possibly speak up for myself. They turned my normal human anger at being in that situation, being labeled, and treated in that patronizing way, into a symptom of my brain disease. I thought my whole life was over. Finally, I decided I had to get out of there, to do whatever I had to do, to go along to get along.”

From the end of 1966 to the summer of ’71, Judi dreamed of getting together with other people who had been through the same thing she had. One day in the summer of 1971, she came across an ad in the Village Voice for a meeting of the Mental Health Liberation Project.

“It was in a church, and it was full of people who showed the same sense of outrage I felt, something only insiders knew. I was not alone and not crazy to feel this way, and it was political, our basic civil rights. We had something,” she said.

“The profession ignored us until the late 1970s, early ‘80s. Then, the National Institute on Mental Health put together a meeting of ex-patients, family members, and professionals. It was often contentious, but it was genuine dialogue,” she said.

In the ‘90s, the idea of recovery began sweeping through the ex-patient community, with self-help programs, and funded peer support and drop-in centers. Gradually, the mental health professionals picked up the word “recovery,” and adopted it as their goal, and the goal of their agencies. In February 2006, the federal Substance Abuse and Mental Health Services Administration (SAMHSA) issued a policy statement that said, “Recovery will be the focus of all the mental health services we support.” It attached a list of 10 elements needed to make a service “recovery based.” It included clients setting their own goals and participating in their own treatment planning, and other things that could have been copied directly from Mary Ellen Copeland’s pioneering recovery program, and she is an ex-patient.

Doesn’t all the talk in government and treatment agencies, as well as consumers, show some progress, or some change, I asked Judi.

“It would, but I don’t trust them and I don’t believe them,” she said. “Recovery is a consumer invention, something we live. The word was picked up by the field, but professionals can’t offer us mutual support, purpose, friends and companions. a community outside the mental health world. That takes lived experience, not labels. Disturbing, destructive things in life are not symptoms. People changed and grew, despite what the professionals thought, and told us, in the ‘70s. They can’t give us recovery-based services unless we have really free choice, no labels, no unequal power dynamic between the professional and the consumer, and absolutely no coercion. If it’s not completely mutual and voluntary, it’s not recovery. I’m not even sure they know what recovery is.”

“It’s still civil rights. ‘I’m OK and you’re sick,’” she said. “People are still demeaned, disregarded, and infantilized. They still say we can’t say what we need. NAMI (the National Alliance on Mental Illness) still says we know better what’s best for our relatives than they do, and they need to be treated with a drug. The money they take from drug companies...!”

Finally, I asked her if she still rejected the idea that there is a brain disease, despite recent discoveries made possible by modern imaging technology.

“They can show changes in the brain, but they can’t say whether the changes caused the emotions or the emotions caused the brain to change. It’s still chicken-and-egg. I’ve stopped paying attention to those studies,” Judi said.





## Still fighting

Interview with Judi Chamberlin

Betty Reid Mandell

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*<sup>1</sup> 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. She 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.)"

*I interviewed Judi 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 and Reiki massage at home myself. The hospice organization that I had before included Reiki massage. 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 take 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: You have spoken at conferences all over the nation and the world. In the interview I had with you in 1993 for my human service text,<sup>ii</sup> you said that 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 you and asked you to participate in the first conference involving users as well as researchers. This surprised you, 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 hear only 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.

In that same 1993 interview, you said that 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 patient's 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.)

You have tried to promote dialogue between AMI and MPLF. You said that 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.

You said that some people accuse the MPLF of being totally opposed to drugs, but you 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. You tried drugs but didn't find one that helped you. For you, drugs didn't work, but you wouldn't tell anyone else what to do.


Following is your discussion of drugs and treatment in that 1993 interview:

JC *[from the earlier interview]* 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 Judi says 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. Judi believes 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. Judi thinks 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).


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](http://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, [www.power2u.org](http://www.power2u.org). 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 died recently because the psychiatrist prescribed an anti-psychotic.

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 Audre 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 Audre 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.

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

JC: Until fairly recently, homosexuality was considered a disorder the 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. My e-mail is [Chamjudi@aol.com](mailto:Chamjudi@aol.com).

BRM: I have looked at your blog (<http://judi-lifeasahospicepatient.blogspot.com>). 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.

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

<sup>1</sup> Betty Reid Mandell and Barbara Schram, *Introduction to Human Services: Policy and Practice*. Boston: Allyn & Bacon, 2009, pp. 47-51.

Betty Reid Mandell is co-editor of *New Politics*, and a welfare rights activist.

Pull quotes: p. 2 — 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.

p. 4: 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.





*Dear Marty,*

*I so wish I could attend but I live in the UK and can't get out. My thoughts are with you and Julie. I include something I've written. Please would you give Judi a hug and a kiss from me, Louise, a British survivor who will always be grateful for having known her.*

*Take care*

*Love Louise*

## **Memories of Judi Chamberlin**

### **Dignified Activism**

**Louise Pembroke**

I first met Judi in 1988 at the start of my own activism at the annual Mind conference when her seminal text *On Our Own* [first published in 1977] was published by Mind and deservedly won the Mind Book of the Year Award, then at a landmark conference in Brighton entitled 'Common Concerns'. Mind also supported this 3 day event with international survivor speakers from the USA and Canada such as Judi, 'Howie the Harp' and David Reville. Practically everyone who was active in the 80's either attended or knew what happened by word of mouth from that conference, it was a pivotal moment in time, just as when our Dutch peers came over to assist British survivors in the formation of Patient Councils. Judi was inspirational to me as there were few women leaders in the British survivor movement at that time, and here was a world leader talking about user-run, not user-led services which for some of us was a dream we thought not possible and Judi had made it real in her country.

What was so striking to me about Judi was her total lack of ego and 'stardom'. Frankly, even if she had been I certainly would have forgiven it because she had the intellect, hard work and unconditional compassion to back everything she did, and at a time when there were not the financial rewards there can be now. Judi wasn't interested in kudos and personal status, all she was interested in was furthering the greater good of survivors, for us all to be met with love, compassion and with patient controlled alternatives to psychiatry.

Face to face, one to one, she was no different, she was interested to share experiences with us, would give us her full attention and was kind and generous. She always made you feel like whatever you had to say mattered. Judi was dignified, I never saw her raise her voice or rant at anyone, yet she could calmly and effectively argue the most seasoned opponents under the table. She was also a fine academic but a good one in that she could make a well read argument accessible to anyone.

The year after I spoke alongside Judi at a conference in Montreal for Canadian survivors. We also shared a hotel room and unsurprisingly Judi was a gracious roommate. To sit beside someone who was a living legend to me was very special indeed. Even when I know she disagreed with her peers she would do so quietly and with respect, never putting down another's thinking. She made people think not only by the sheer strength of her words, but also how she imparted them, measured, powerful. She was deadly serious in her work, driven and dedicated. Judi was a role model to me because she embodied how I felt activism should be, how we could best conduct ourselves as activists. She was also aware of how difficult it could be too and how survivors were also capable of cannibalizing each other and to my mind she led by example by keeping her focus on the work in hand.

Whenever Judi visited the UK she would take me and Peter Campbell out for a meal and we treasured our time with her and valued what we learnt and shared with her.

Her last sentence 'nothing about us without us' from her 2007 WPA speech is burnt into my memory. Judi is a bright shining beacon to survivors across the world, and I thank her with all my heart for all she has given us, and for what she gave me.

Louise Pembroke





## A TRIBUTE FOR JUDI CHAMBERLIN CELEBRATION OF A LIFE

Mary O'Hagan

*I'm a colleague and friend of Judi's from New Zealand. I can't come to her celebration but I would like to share this extract from my nearly completed memoir which I will be dedicating to Judi.*

By now I'd started to make some sense of madness and to understand what was wrong with the mental health system. I knew there had to be a better way of responding to madness but I couldn't find it. So I kept searching library shelves for the answer, not quite knowing what I was looking for. Then one day, a few months before my last admission, I was scanning the psychology section when I noticed a book called 'On Our Own: Patient-controlled alternatives to the mental health system', by an American called Judi Chamberlin. I opened the book and scanned the introduction:

'For too long mental patients have been faceless, voiceless people. We have been thought of, at worst, as subhuman monsters, or, at best, as pathetic cripples...

It is only with the emergence and growth of the mental patients' liberation movement that we ex-patients have begun to shake off this distorted image and to see ourselves for what we are - a diverse group of people, with strengths and weaknesses, abilities and needs, and ideas of our own...

Our ideas about psychiatry, about the nature of mental illness, and about new and better ways to deal with people undergoing emotional distress, differ drastically from those of mental health professionals...'

With these words, I knew I'd struck gold. I'd already read several autobiographies of mad people who wrote vivid descriptions of their madness and how they were treated. I'd also read anti-psychiatry books written by professionals and academics who argued that madness wasn't a medical condition. But this was the first time I'd read anything by a mad person that challenged the ideological foundations of psychiatry through an analysis based on her own experience. It was my introduction to the mad movement.

Chamberlin started by writing about her own experiences in the mental health system. It resonated with my own; her initial hope that professionals would help her, and her growing awareness that they were controllers rather than healers; the crumbling of her personhood as the hospitals took away her possessions, her liberty, her self-belief and the hope that she would ever recover. Chamberlin's experience was worse than mine; she was held down and forcibly treated, locked in rooms and told she would never leave the hospital.

Chamberlin recovered some years after her hospital admissions in a ex-patient run alternative where she was respected, listened to, free to come and go and able to express her feelings. In the book she describes ex-patient run alternatives in the USA and Canada where participation was entirely voluntary, where everyone could both give and receive help, and where there were no hierarchies. Suddenly, after years of wondering if there's a better way I had found it.

This book validated the experience of madness more than anything else I'd ever read. It slammed the medical model and argued passionately against the power of the mental health system to force treatment on people and control their lives. The mental health system needed to be replaced by responses that respect the experience of madness, and where people could choose what works for them.

I never took Chamberlin's book back to the library. Over 20 years later it still sits on my bookshelf, tattered and browned at the edges, one of those rare books that showed me a new world rather than a familiar world revisited. Between the lines it showed me I could do something good with my madness, that there was a place in the world for mad people to critique the mental health system, to organise, and to come up with better responses to madness than hospitals, drugs and coercion.

Though I didn't quite know it at the time 'On Our Own' became the launch pad for my life's work.

*Thank you Judi, a thousand times thank you.*

Mary





## Judi Chamberlin: Celebration of a Life Tributes

### Alvelo, Patria

Dear Ms. Chamberlin,

I am very sorry to learn of your illness. I found an article on freedom-center.org encouraging people to email you, so I decided to drop you a line. I've actually been debating whether or not to email you for months now. I am a second year graduate student in the Women's History program at Sarah Lawrence College and I am currently finishing up my Master's thesis on the psychiatric survivor movement. I myself am a survivor, . . . Clearly, this is an issue that's very personal (and political!) to me.

I just wanted you to know that I am trying, on some small level, to give voice to the movement and educate people about it. If you'd like, I can send you a copy of my thesis when it's finished.

Stay strong!

Sincerely,  
Patria Alvelo



### Barbieri, Donna

Dear Judi,

I'm truly sad that I can't be there in person to share in your celebration, but know that I am there in spirit and hold both you and Marty in my heart. You, my new friend, are a woman of style and incredible grace. I admire you for all that you've championed in your life and am humbled by the legacy that you've bestowed upon others. It is truly inspiring. As Marty's longtime friend, I must also say thank you for all that you have brought to Marty's life. In opening your heart and your home to him there is a spirit and a light in him that shines brighter than I have ever seen before.

"Just when the caterpillar thought her world was over . . . She became a beautiful butterfly." [Author unknown]

Warmly,  
Donna

### Barker, Phil

Dear Judi

This is Phil Barker writing from Scotland. Hopefully, you will recall meeting with me and some of my English colleagues at Dan Fisher's house - probably around 1996 . . .

A lot of water has flowed since then and I was sad to read of your situation, but uplifted by your doggedness. Not surprising, of course, given your story. You continue to be an inspiration to so many people.

I just wanted to wish you and Martin a great day on the 20th. It sounds as if you will be overwhelmed with friends - old and new. I shall be thinking of you.

Yours in Friendship  
Phil

Closing Ceremony Alternatives 1985



### Brown, Neal

Hi Judi,

I have always admired your dedication to the cause of empowerment and freedom and your courage in taking on the psychiatric establishment. I continue to admire your courage in facing down illness and celebrating life. I know that August 20th will be a day to remember. Thanks for all you have done for so many people for so many years.

Love, Neal

Director, Community Support Program / Center for Mental Health Services  
Rockville, Maryland





### **Caras, Sylvia**

I probably met Judi at a NARPA meeting some years ago. I was a newcomer, a group was in the lobby arranging where to go for dinner, Judi graciously included me in the plans. I heard then and have kept noticing, how Judi doesn't get distracted, uses good words to keep the focus on 'our own' issues, insists on respect and inclusion that she and we deserve.

My thoughts will be with you all.

Sylvia Caras

*People Who – Internet based support group*

### **Carl, Deborah**

Hi Judi,

I am a mental health practitioner at a community mental health center in Portage County Ohio. I have been a fan of your work for years and have only seen the news of your life as a hospice patient today. I have been involved with the state of Ohio's efforts to train traditional staff about the recovery and consumer survivor movement and in doing work on a pilot project, I ran across the news and your blog.

I am such a believer in synergy and good energy and a merciful Universe that I just know this was not a chance happening, but a purposeful one.

I will, from here on out, think of your health and wellness daily with care and good will. The world's full of wonder and you have most certainly contributed to that wonder as I have pursued my life's work.

May the sun rise to meet you! Be well!

Sincerely,

Deborah Carl

*Coleman Behavioral Health, Portage County Ohio*

**Judi with  
Justin Dart  
Father of the  
disability rights  
movement**



### **Carleton, Dayna [Caron]**

Dear Marty and Julie,

We just got our internet service installed in the woods of Vermont yesterday, so I am totally behind on e-mail and was wondering if you had scheduled the celebration. God willing and the creek don't rise, we will be there and are thrilled to be invited. Thank you so much for organizing this event and I am looking forward to meeting both of you. I will look at the invitation in a moment, but hope this will give you a count. I'll bring my husband, Jesse, as well. It will be grand to celebrate Judi! Thanks again and see you soon!

Love from Dayna (Caron) Carleton

### **Cheverton, Jeff**

Dear Martin

Judi visited us in 2007 as our guest keynote speaker at The Altering States Conference in Brisbane, Queensland. She came to our conference to speak about the need for consumers and survivors, not just to lead the movement, but how survivors and consumers have always led the movement for change in mental health. So many people I spoke to had read "On Our Own" and were excited to meet her in person. Judi did not disappoint. Despite not feeling terribly well at the time, she delivered a rousing key note speech at our conference and set the scene for a focus on the most important people in the mental health system: those the system is meant to help. There are many, many people all the way over Queensland who feel warmly to Judi and her leadership. We're glad we've still got her, we're sad that she might soon be leaving, but she must be so proud of what she's leaving behind.

Warm regards

Jeff Cheverton

*Chief Executive Officer*

*The Queensland Alliance / Peak Body for the Mental Health Community Sector*





**Clay, Sally**

Hi Marty -

Thanks for the gracious invitation to Judi's celebration. I am unable to attend, but my thoughts and heart will be with all of you there, and especially with Judi.

Warm regards,

Sally Clay

*Long time activist in  
Maine, then in Florida*



**Collier, Carole Hayes**

I totally regret not being able to be there with you all in the flesh but certainly in spirit! Marty I met you with Judi when she came to the Everson in Syracuse for the Suitcase Exhibit. I have met up with her many places around the globe including Paris, Dublin and Toronto and will sorely miss her heart and tenacity of spirit for the movement. The next place we meet up will probably be an even finer experience than the great ones of our pasts. I am on at least my 20th copy of her book.....and always await her new words of wisdom!!! Be one in Spirit and solidarity for hope and change!!! Best

Carole

*And later . . .*

Greetings, Marty and Judi. I responded the other day that I could not attend Judi's celebration but just couldn't be ok with that. My husband, Paul Collier and I will both be with you on this special day of celebration. I recently had a loose screw removed (people always suspected that!) but this one was in my knee. I will try to be more mobile by the date to travel but will at most be using a walker I do believe. I do so look forward to being together with you all for this powerful occasion for the whole movement!!!! Best

Carole Hayes Collier

*Director, Community Based Peer Initiatives / Transitional Living Services  
Syracuse, NY*

**Crowley, Kathleen**

Judi,

I only just read that you have hospice coming in and are welcoming emails. We have never met, but I wish we had! I am currently sitting next to my husband's hospital bed, at one AM, and only have a second to send this email. But I wanted to thank you for all of your amazing, humane, passionate and compassionate work. You are the bomb!

I also read that you would like to hear about some of the work others are doing, that it makes you feel connected. Boy oh boy, do I understand that. Because of your work, the world seems a little smaller, a little safer and a lot more beautiful. I hope that you are able to find joy and peace in the beauty you have planted. If you happen to have a few minutes, I would LOVE you to listen to one of our new podcasts. We just began a weekly podcast, and only have two up, with a new going up early next week. Our second one is approximately 15 minutes long and it is lovely, I think. A new vehicle to bring and build hope and life and healing. (It is available at [www.procovery.com](http://www.procovery.com), at the top of the page, there is a button for podcasts.....)

I very much hope to meet you one day. But even if I don't, I feel I already have. Take very good care of yourself. I wish you all good things.

Kathleen (Crowley)



**Coldham, Tina**

*A message for Judi from England, UK*

Dear Judi

The path you skillfully trod, makes it easier for us to follow and give us strength to tread onto paths anew. Thank you.

Tina Coldham

*Chair - National Survivor User Network*



### **Dosick, Jonathan**

Greetings Mr. Federman,

I'd be honored to attend the Celebration for Judi! As a fellow consumer/survivor activist, her work is very influential and important!

Jonathan Dosick

*Coordinator, Five Fundamental Rights Enforcement/Fresh Air Rights effort  
Waltham, Massachusetts*

### **Ellenbogen, Dr. Mark**

Dear Judi- I will try my best to be at your celebration-I have known you for years and have always felt that you are a very exemplary person with steadfast character and kindness to others. My best wishes.

Mark Ellenbogen, M.D.  
*Judi's longtime pulmonologist*

### **Entine, Jean**

Marty, this is an incredibly wonderful tribute. I am deeply moved. Unfortunately I will not be in town then . . .

Am sending you big hugs as you go through this last chapter with Judi.

Jean

### **Fendell, Susan**

Judi was my introduction to the consumer movement. How lucky was I to be initiated by a forceful advocate as well as a strong feminist. Please give her my love and my wish that immortality become a reality today.

Susan

*Patients' Rights Lawyer*

### **Finkle, Mike**

I hope you have a joyful and fantastic celebration for Judi on August 20th.

Please send my best wishes to Judi - we are all very grateful to her for all her advocacy work over the past 30 years – she is truly a visionary and pioneer.

Very best wishes,

*After sending that note, Mike sent a number of wonderful photos from Judi's past, some of which are included among these tributes. The following is excerpted from the letter he sent with the photos:*

Dear Judi:

Greetings from all your friends in Baltimore. Unfortunately, we will not be able to be with all of you at the August 20<sup>th</sup> "Celebration of Your Life" event. Hope you have a wonderful time. We are enclosing some pictures from past events to remind you of what your courageous advocacy activities have accomplished over the years. If not for you, we would not be what we are today here in Maryland. Enclosed are pictures from our first statewide mental health consumer conference in Maryland from June 1982, where you were the keynote speaker. The conference was held at the University of Maryland, Baltimore County campus and we had over 200 people attend, including Joe Rogers who was then living and working in New Jersey.

Also included are pictures from the first Alternatives Conference which On Our Own, Inc. hosted in Baltimore in June 1985. In addition we have included some other pictures of other consumer friends of yours from around the country – Sally Z, Rae U., Jay M., etc. – in addition there is a picture of you at one of the Self Help Live shows that Paul Dorfner did many years ago.

We are truly grateful for all your work over the years and greatly appreciate what you have done for mental health consumers/survivors around the world. You truly have made a difference – you changed the world. Thank you!

In friendship, peace and love,

Mike

Mike Finkle

*Executive Director  
On Our Own of Maryland, Inc.  
Baltimore, Maryland*





**Freedman-Gurspan, Marion**

I am sorry I will not be able to attend. I do remember many of Judi’s words, and quoted her just today. The goal of DMH services is to enable those involved with the system to be able to have what everyone wants – a job, a place to live, and a date for Saturday night. It sums it all up. It has been my pleasure to participate on the MH Planning Council with Judi.

Marion Freedman-Gurspan

*Director of Policy and Planning*

*Division of Child-Adolescent Services / Department of Mental Health, Massachusetts*

**Goldman, Carol K.**

Dear Marty and Julie,

I will be there on Thursday, Aug. 20th. I have never met Judi but have been active in the mental health world as someone diagnosed with bi-polar illness. I have given talks about my life and coping with stigma and published a paper with my psychiatrist about a technique we co-created to document our sessions, entitled “Co-Documentation”. I know so many people including me have benefited from Judi’s activism.

Carol K. Goldman

**Gottler, Janet**

Thanks so much for the invitation, Marty, but I have a conflict and won't be able to come. I hope it goes well! What a wonderful idea for a gathering.

Janet

**Gottstein, Jim**

Dearest Judi,

I so wish I could be there for the celebration of your life. What a life it has been. I have been honored to know you for even the short time that I have. You have been such an inspiration and example for me that I can not even begin to express the depth of my feelings about it. I doubt you have any idea how much of an impact your steadfast adherence to the principles of truth, justice and plain humanity in pursuit of rights for people labeled crazy has had on me. Your intelligence in pursuit of this is second to none. More importantly, your integrity is absolute. I think it is maybe the extreme intelligence combined with your absolute integrity that makes you the giant that you are. Even though I haven't communicated with you much, I think about you almost every day. Your passing will leave a great void in my life as it will in so many others. The Jewish tradition is that people live on in the memories of people, and in this sense you will be immortal for what you have given to those of us who will be carrying the torch after your passing. .

With Eternal Love,

Jim

James B. (Jim) Gottstein, Esq.

*President/CEO*

*Law Project for Psychiatric Rights*

*Anchorage, Alaska*

**Judi  
with  
Tom Behrendt  
at  
Highlander**



**Heiger, Gloria**

Dear Martin Federman,

Judi is my cousin. Sorry our family cannot attend.

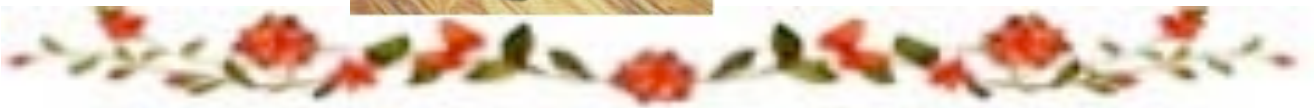
Please give Judi our love and admiration.

We have admired her work,  
and read her fascinating book.

We are with Judi in love and in spirit.

Love to the family and we will love Judi forever!

Gloria, Nathan, Joanie, Carl and Bobby.





### **Kapp, Wendy**

Hi Martin,

How wonderful it is that you are doing this! Judy transformed my life and the life of so many others. How I wish I could come. I will be there in spirit however. If you remember please give her my love.

Yours in Health, Prosperity and Vibrantly Alive Peace.

With Warm Regards,

Wendy Kapp

### **Knutsson, Hope**

Dear Judi,

You have touched the hearts and minds of 2 generations of Icelanders with your message about empowerment and recovery! When I arranged to bring you to Iceland in 1986 I was a mental health professional suffering from burnout after working for almost 20 years in the health care system on both sides of the Atlantic: first in NYC and then in Reykjavik. I was head of an ex-patients self-help activist organization in Iceland when I read "On Our Own" and decided that Icelanders had to see and hear you in person and to know that mental health services could be very different from the way they had been up until then. Back then your message to the people of Iceland was startling and new. I don't think many people were able to believe that what you were talking about then was really possible. It was thrilling to get you back to Iceland in 2006 and let a new generation of survivors and families hear a lot more about the empowerment movement now that several organizations in Iceland were up and running, using the empowerment model.

What started with a correspondence about mental health issues became a warm friendship over the last quarter of a century as we found we had so many things in common. I regret that I cannot be with you for this celebration of your life. I wish everyone could experience attending such an event where so many people who love, respect, and are grateful to you show their appreciation while you are here rather than after death! You are a remarkable person who has changed and improved the lives of tens of thousands of human beings all over the planet! Thank you for being a part of my life and for waking up the tiny nation of Iceland to the important things you have had to say for all these years.

All my love,

Hopey

***Later***

Dear Judi,

I read your blog every day and I think about you every day. I hope that you feel deservedly proud of your accomplishments. I hope that you take comfort in the awareness of the huge, positive impact you have had on the world! Not many people do that in their lifetime. You have influenced the lives of tens of thousands (perhaps millions by now) of people around the world through your writing and speeches. You have humanized mental health services and inspired so many people to empower themselves. You have accomplished much more than most people. Thousands of people are grateful to you. I think that it is probably easier for people who have accomplished a lot in life to face death knowing that their lives have had so much meaning and that they have made the world a better place. I admire you greatly and am so glad that you have touched my life.

Love you,

Hopey

Reykjavik, Iceland

### **Kovary, Myra**

Dear Marty, Julie and Judi,

Thank you so much for the invitation. I'm sorry I can't make it to the celebration but my spirit will be there with you all. Please give my very best to Judi and I hope the celebration brings her much happiness.

With love,

Myra Kovary

*Activist/Advocate*





**Lara, Helen**

Hi Judi,

Laura Van Tosh sent me your email address and directed me to your blog.

I worked in a self-help center in Santa Rosa, CA for 10 years and started another Wellness Center with the MHSA money for the last year when I lived in CA. I moved to Oregon last February and attended Alternatives last fall where I bought a copy of your book. I thoroughly enjoyed it and asked the MHO to purchase a copy for each of our 6 CROs (Consumer-run Organizations).

I know that it has been out for many years but I am really not much of a reader. It is very difficult for me to concentrate and not to get distracted when I read something but when I saw it, I really wanted to read it. Thank you for writing it.

Anyway, I do really admire the work that you have done and the commitment to clients/survivors and the movement.

I hope you have a good day tomorrow.

Helen Lara

**LeFave, Patricia**

Dear Judi,

You don't know me but I just want to say I too find you very spiritual. Spiritual and 'religious' are not necessarily the same thing. Though I do believe in God, I do not need anyone else to believe it. Should we meet in a next dimension of being we can argue over it and laugh then.....

I have been fighting the system in Canada since 1994 and many times I have felt disgusted and been tempted to just stop talking altogether. But when I see someone like you still interested enough in all of this to bother to keep on talking, even from your hospice room I feel a renewed spirit to carry on. Ironic huh? Also I am both the psychiatrized as well as a support worker with much experience in palliative care. If I can give you any hints to make this journey easier don't hesitate to let me know. Even if it is just an ear to hear what others may not want to hear? I figure I owe you one for your inspiration.

Thanks for sharing the whole trip with us all out here in cyber space...Your presence on Earth has made a big difference for many people. Glad you could come and glad you decided to stay awhile despite all the pain and loss. I do believe in God and if there is a dimension of being to go to beyond this one, I think you will be there too. If not, well, I will be on my way for the big long nap soon too...which doesn't seem so bad no matter how you look at it.

Patricia Lefave,  
*Canadian ex-mental patient  
and psychiatric survivor.*



**Judi  
with  
Peg Sullivan  
and an  
unidentified  
woman**

**Lopez, Diana**

Marty and Judi-

I do wish you a wonderful, joyous time with friends from far and wide. I will be remembering you on that day very fondly.

Lots of love and hugs,

Diana

*Judi's PCA*

**Lucas, Beth**

Hello,

My thoughts will be with Judy and all of you as you celebrate her at this event.

Beth Lucas

*Director of Quality Improvement  
Office of Quality Management and Policy / Department of Mental Health  
Boston*





**Mendelson, Lorre Leon**

July 20, 2009

Dear Judi and Marty, Thank you for this opportunity to celebrate Judi's spirit and her accomplishments. It was probably close to 15 years ago I first learned of Judi and Rae at about the same time-perhaps it was Rae [Unzicker] who introduced us. Our connection has been a very strong one for me: touched by your strength, focus, determination and fight. Like many great leaders, you have inspired changes and changed many of the laws and social injustices that have hurt so many of us for so long. People who remain long after we are gone will benefit from your courage and fortitude whether they know who instigated those or not. But I will know, Judi. And I will continue to spread your message of rights, ethics and persistence. That one person CAN make a difference and a group of committed individuals CAN make a difference comes to light in your being. Your words and rights are heard from the east to the left coast, throughout Turtle Island.

We who have awakened celebrate your gifts, your sense of righteousness and generosity of time and direction. Whether you are here physically or in spirit and memory, Judi, you will always be close to me as I work toward freedom and choice for all of our people.

Thank you for letting me in and passing on your work.

With sadness, regard and love,

Lorre Leon Mendelson

*Advocate/Activist*



**Judi  
with  
Sally Zinman  
at  
Highlander**

**Mikowitz, Tina**

Dear Marty & Julie,

I would like to come to the celebration but do not know if I can.

So here are my small remembrances and tribute.

I first became aware of Judi's work in the early days of what was then the mental patients liberation movement. Our paths crossed but I did not become very active then.

In 1985, Judi was one of the people who created the National Association of Psychiatric Survivors - to be a national organization that didn't take mental health funding (if I remember correctly). Now in hindsight, seeing the rise of NAMI, I understand why the movement should have stayed together and tried to make it work to create a good national organization.

Judi and I were both in Japan, I think for the DPI world assembly in 2002 or 2003, and we were invited to meet with the user/survivor movement. I recall Judi spending most of her time listening - which was inspiring to me. When Judi was co-chair of WNUSP, she lent her support to the work on the Convention on the Rights of Persons with Disabilities and was always ready to make a statement against forced psychiatry.

If I understand correctly, Judi was also one of the people who were visionary enough to connect us up with the disability rights movement - before most of us thought that identifying as "people with disabilities" could be revolutionary. The NCD Report From Privileges to Rights - Judi was involved with the testimony taking at a NARPA conference, that made up the substance of the report. And I recall her giving a workshop with Marca Bristo at that conference to introduce the psych survivor movement to the disability movement & vice versa.

I know Judi must be happy to know about the U.S. signing the CRPD. And I hope that we in the movement can dedicate ourselves to continuing the fight for human rights until we win. We will win; everybody takes a step & lends a hand to the ones who come next. Judi & the other founding mothers & fathers of the movement have given us a powerful legacy.

Judi, you're continuing to be who you are, and to stay in the struggle to the end, is its own kind of inspiration.

Thank you.

Take care,

Tina





**Murphy, Ned**

Judi:

You may remember me from when I served as commissioner of mental health in the mid to late 80's. We met a number of times during that period and I was very impressed with your advocacy and insight into the system. I have seen and heard your name since then and I know that your leadership role has grown and you have made an even greater impact over the years. I did not know that you were ill until I read about it in the Sunday Globe. I am very sorry to hear it.

I wanted to write to thank you for the enormous contribution that you have made to the lives so many people. It is hardly a surprise that you are confronting your latest challenge with the same spirit of determination and openness that has characterized so much of your work. Please know that I will follow your blog and that you will be in my thoughts and prayers.

Ned Murphy  
*Former Massachusetts Commissioner of Mental Health*

**Nettle, Mary**

Dear Martin & Julie,  
Hope all goes as well as it can. Thinking of you all from across the Atlantic.  
Lots of Love,  
Mary Nettle  
*Mental Health User Consultant  
Worcester, England*

**Judi  
And  
Celia Brown  
at  
Highlander**



**O'Leary, Tim**

Hi,  
I regret i will not be able to come.  
My wife and i are in Texas that week.  
I hope it's a great evening for a great lady.  
Tim O'Leary  
*MA. Assoc. for Mental Health  
Boston*

**Ostrow, Laysha**

Hi Marty,  
I would like to attend Judi's celebration. I'm working with Dan Fisher and others to strategize on developing peer-run crisis services in MA, and he forwarded me the invitation, but I also work at HSRI where Judi is on the board (Val Bradley forwarded all of us the invitation as well). Her book was very important to me as a consumer and a researcher, and in fact was the first thing I was given to read when I joined HSRI.

Laysha Ostrow  
*Human Service Research Institute  
Cambridge, Massachusetts*



**Judi  
in Sapporo, Japan  
2003**





**Owen, Eleonor**

Hi Judi & Marty,

Perhaps you don't remember me, but we first met in Madison, WI when a small troop of parents created NAMI. You were a feisty young woman resisting the intrusion of PhRMA and Families and we were a feisty group of parents venting our rage against a system that was criminalizing persons who were being tossed out of state hospitals onto the street.

Since then all of us have grown and each of us at that conference in 1979 have made major changes in the publicly funded mental health system. You have clearly led the way for individuals to speak "In Our Own Voice." And it has been great! Unfortunately, while NAMI has grown in visibility, I believe that it no longer speaks or focuses upon the most vulnerable who are unable to speak for themselves -- those in jail, shelters, on the street or in prison.

So, my heart goes out to you. Celebrate!

My husband of 60 years died a couple of years ago and I wish he had been able to hear the wonderful things persons said at his memorial. Enjoy your well earned celebration.

Eleanor Owen,  
*Treasurer, NAMI Greater Seattle*

**Perlin, Michael**

I had no idea at all. I cannot be there, but please send Judi my love. We have known each other for almost 35 years, and though we have not seen each other much in recent times, I have always cared for her and admired her so much....

Michael Perlin  
*Professor, New York Law School*  
*Author of many books and papers on patients' rights and Bob Dylan fan extraordinaire*

Judi with Tom Behrendt at Highlander



**Poole, Ruthie**

Hi Marty,

My name is Ruthie Poole. I work at the Transformation Center and am on the Board of M-POWER. Judi has been one of my heroines for years. I'm thrilled you two are having the celebration to honor her!

Unfortunately, I will be conducting a training in Taunton until 4 PM on Aug. 20th. I will rush back and hopefully be able to join you at the end of the celebration.

Thanks again for honoring your wonderful partner,  
Ruthie

**Port White, Lisa Dee**

dear julie and marty,

thank you very much for inviting me to your celebration of life. i'm afraid i won't be able to be there. i hope you have a wonderful celebration and that you are able to enjoy every moment of it.

thanks again,

lisa dee  
*Touch of Comfort*  
*Massage Therapy for Hospice Patients*



Judi with Laura Prescott





**Rogers, Susan**

Marty,

I'm sorry but I will not be able to attend Judi's celebration, as much as I would like to! I live in the Philadelphia area, and other commitments make it impossible for me to travel up to New England at that time. However, I will be thinking of Judi on that day!

Thanks for the invitation and all good wishes for a wonderful event,

Susan Rogers

*Director*

*National Mental Health Consumers' Self-Help Clearinghouse*

**Ross, Daniel**

I just ordered your book and subscribed to your blog.

You are the best!

I hope in some small way I can have the impact you have had on our community. Towards this end I will head off to law school in the fall.

With the greatest respect and admiration,

**Salzer, Mark**

Dear Judi,

I hate that the extent of your illness is the cause, but appreciate the opportunity to let you know how much influence you have had on mental health systems and on me personally.

I have been blessed with opportunities to do some work that I think Rogers and other colleagues at the Clearinghouse are a big part of the Center. . . . Our focus is on doing research that identifies contextual barriers to community integration and effective supports.

Our group is also doing lots of training and technical assistance trying to help providers, consumers, systems, etc. understand the importance of addressing barriers -- "No, not 'illness' barriers, but all the environmental factors, including discrimination that our provider community helps to perpetuate, that plays a huge role in lack of community participation," and develop strategies for addressing these barriers, as well as supports that are effective.

I love this work. Hopefully, in some way, the research will have an impact that moves us a little toward the vision

Mark Salzer

*Associate Professor and Director*

*UPENN Collaborative on Community Integration of Individuals with Psychiatric Disabilities*

*Investigator, VISN 4 MIRECC, Philadelphia VA Medical Center*

**Simpson, Terry**

Dear Marty

I can't come to Judi's party in August - its too far to come from Leeds in England. But I wanted to say how much Judi has meant to me. I had just found the survivor movement about the time 'On Our Own' was MIND book of the year here in England in the late 1980s. It had a tremendous impact on me - so tough and uncompromising in one way, and yet so inclusive and hopeful in another. I travelled to London with my friend Migs Noddings who had set up the survivors group here in Leeds, and who was a keynote speaker at either the launch or the award ceremony at MIND. It was incredibly moving for me. Migs and I and some others kept talking about survivor led crisis services, purely based on Judi's writings, and eventually we got people here in Leeds to listen, and got some funding for Leeds Survivor Led Crisis Service, which has been running now for several years. It was funny that when we really started to research survivor led crisis services we found very little over here - somehow we'd imagined there was lots! That book just gave you so much confidence to get up and do things!

I hope you'll pass this on if possible to Judi, with all my love. We had a Mad Pride party where I saw Migs last night - I forgot to ask her but I'm sure she sends all her love too.

Terry Simpson



**Judi with Marcia Lovejoy  
On Our Own Conference  
1982**





**Stith, Byron**

Dear Judi:

I regret that I will not be able to come to your celebration of life, but I want you to know that I respect the strength and courage you have shown during your journey.

I remember when I first met you when I arranged a recovery workshop here in Virginia at which you facilitated. It was a hot summer day, so I bought two bottled waters on my way to pick you up from the airport. I met you at the gate with the waters. Unfortunately, I was so nervous that I drank out of both containers. You were gracious as always and the feedback that I got from the workshop participants was overwhelmingly positive.

I am keenly aware of the foundation the you have laid down for me in the consumer movement and more specifically in my present position as a disability advocacy specialist for the National Disability Rights Network. To my knowledge, you were one of the first and few consumer survivors to serve on our board. And now, I am the first consumer/survivor that I know of to work for NDRN. I appreciate the foundation you have laid down for me, and I know that I am standing on the shoulders of giants.

It's good to know that while I may be the first and only identified consumer to work at NDRN, I am not on my own. And that's the way it should be.

*We cannot banish dangers, but we can banish fears.  
We must not demean life by standing in awe of death.*

**David Sarnoff**

I appreciate the opportunity to celebrate your life and want you to know how much your life has meant to me.

Take Care

Byron Stith

*Disability Advocacy Specialist  
National Disability Rights Network  
Washington, DC*



**Rae Unzicker,  
survivor leader &  
Judi's best friend.  
Died 2001**



**Judi at  
Freedom Rally  
Bethesda, MD  
2002**

**Swan, Dan**

I do not know what to say to you. After 20 years of seeing powerlessness as a consumer, right now things are changing more than ever before. This wouldn't have happened without you. It's almost beyond belief that we have a voice now, and I don't know what to say to thank you that could do justice to what you've done.

I'm going to get an M.D. and a J.D. and more importantly, am going to fight tooth and nail to crush the forces that have oppressed us for so long. There are better people than me in the world, more kind hearted. I'm not claiming to be anyone special. But I've been fighting. Still fighting, and CAN'T STOP WON'T STOP fighting.

Yours in the cause of equality and autonomy,

Dan Swan

**Talkov, Barbara**

Dear Judi

You and I have never met, but back in the 70's when I was working in drug treatment, you were starting Stone House. So many of us working in drug rehab were either in recovery or needed to be around mh issues. For me, my substance abuse was an attempt at self medicating my own mh issues.

I still have a drawing I clipped from the newsletter you published at the time that said "We would rather be mad with the truth than sane with lies."

It had a huge impact on me & my activism. I remember all the wonderful work you were doing, as women were being shoved into mental hospitals because they/we wouldn't fit into someone else's (society's) definition of how we should be.

Thank you for being you and standing tall for your right to be.

Barbara Talkov

*Executive Director*

*Children's League of Massachusetts*





**Trachtman, Howard D.**

Judi was a great mentor to me. I would like to attend the event on 8/20. I'm hoping to encourage others from the Metro Boston RLC to attend.  
Howard D. Trachtman, BS, CPS  
*Co-Executive Director MetroBoston Recovery Learning Community and Executive Director Boston Resource Center Boston*



**Turner-Crowson, Judy**

Dear Julie and Marty,  
Thank you very much for the invitation to this wonderful occasion. I can't think of anyone whose life is more worth celebrating, and I know it will be a great occasion.  
Please give Judi my very best wishes. I will be with you all in spirit on the day.  
Judy Turner-Crowson  
*Founder, Community Support Group*



**John Allen, Ann Marshall, Natalie Reatig and Rae Unzicker**

**Wallcraft, Janet**

I would love to come but it isn't possible, but I will be there in spirit.  
I pray you will be there in person and able to enjoy hearing how much love and respect we all have for you.

XXXXXXXXXXXXXXXXXXXX

Dr. Jan Wallcraft  
*Activist and researcher Worcester, Massachusetts*

**Weitz, Don**

“She who saves a life, it is as if she saves the world”  
*a saying in The Talmud (paraphrased)*

Judi, through your many years of courageous activism and advocacy for human rights in the psychiatric survivor liberation movement, you have inspired me and thousands of other survivors, advocates and activists. Many of us psychiatric survivors and human rights activists in Canada and other countries continue to be inspired by your work and life.  
As you'll probably recall, in 1979 or 1980 in Toronto, many of us psychiatric survivors changed the name of Ontario Mental Patients Association (the first self-help group of survivors in Ontario) to On Our Own.  
This historic name-change was mainly inspired by your brilliant and moving book On Our Own. Read by many thousands of survivors, activists and advocates, students and researchers, your book spoke and continues to speak to and inspire the personal struggles of our brothers and sisters, it also speaks to and inspires the struggles of the psychiatric survivor and disability rights movements for credibility, independence, and justice. I still treasure the image and memory of you and me blasting the APA shrinks through a bullhorn on Queen Street in downtown Toronto during our historic march and protest at the 10th Annual Conference for Human Rights and Against Psychiatric Oppression in May 1982. During this conference, you played a key role as a trusted and respected member of a support team for the group of 16 American survivors that carried out nonviolent civil disobedience, a sit-in in the lobby of the Sheraton Centre where the APA convention was being held. Two years later in July 1984, three of us carried out a sit-in in the the office of Ontario's Minister of Health because he refused to appoint lawyer-survivor Carla McKague to the government's "ECT Review Committee". Two months later, he appointed Carla.  
Judi, the struggle for human rghts for psychiatric survivors which you advocated, and your dedicated networking with the disability rights movement and other social justice movements continues.  
Your legacy of speaking truth to power, self advocacy and struggle lives, it will continue to live and inspire until we're all free.  
This is your day, this is your time, enjoy and celebrate! L'CHAIM (TO LIFE).  
Don Weitz,  
*Toronto*





**Judi in Athens with  
Rene van der Male  
And Bhargavi Davar  
2006**



**Williams, Ginny**

Hi Judi,

I don't know if you remember me...I worked for you somewhere around 1978-1979 (my dates may be off slightly). I was working as a home health aide through an agency in Cambridge and I think you were living in Somerville. I was assigned to help you with housework, errands and such while you were sick. I could never, ever forget that beautiful smile, so when I saw it again in this week's Boston Sunday Globe, my reaction went from delightful surprise, to dismay. I am still speechless at reading your diagnosis, except to say that I'm so sorry for any suffering you've experienced. I'm also crushed that the world is losing such an influential, gutsy advocate.

I have so many "first" memories that I associate with you, Judi! You were the first published author I had ever met and I was in awe at your accomplishment of writing a book while you were ill. You inspired me to pursue my own love of writing many times over the years. Among other things, I write a column for a NH women's magazine and hope to also publish a book someday, too.

You were the first person I met who owned a waterbed (I later bought one myself ;-)). You were the first person I met who owned houseplants and I remember you showed me how to root the cuttings in water and shared some with me. I discovered I have a green thumb and became a passionate indoor houseplant grower, and later, an obsessive outdoor organic gardener.

Mostly what I remember is how kind you always were to me. Even when I knew you were not feeling well, you always tried to be cheerful. Although I was just a young kid (around 18) and very shy at the time, I remember you talking with me as if I were a friend. You made me feel that I was important and that my presence was valued.

I thought of you often over the years. I have enjoyed reading your blog and admire your willingness to share such a private and difficult experience. I was not surprised to read about all of the amazing work you have been devoted to for the last 30 years. So many lives have been touched with your tireless advocacy! What a powerful legacy you are leaving.

I just wanted you to know that there is one more heart will feel the loss when you are gone, but I wish you peace in your journey.

With love and sincerest wishes for your comfort,

Ginny Williams

"Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved." *Helen Keller*



**First  
Alternatives  
Conference 1985**





## **Williams, Jody**

*Subject: Hi from an 'old' fellow advocate*

Hi Judi, not sure you'll remember me but I sure remember you. Just learned of you latest claim to fame when a Mass. friend told about the Globe interview.

I was Jody Jenkins, then Shaw, now (20 years this time with the same husband!) Williams. When I first crossed paths with you in cross-disability advocacy circles, I may have been with Mass. DPH (mid-70s), the [the-Developmental] Disabilities Law Center, or ArcMass. Later, the Mass DD Council. I also am now 64, pushing 65 so Medicare outfits waste money badgering me.

I retired a few years ago after an eclectic career in state and private sectors, & am in Daytona Beach winters and live aboard a sailboat in Winthrop Harbor summers. I've been fortunate in terms of personal health and having the material basics, but have lost too many friends and relations in recent years to not treasure every minute on this earth and time with grandkids (9), friends, good music, and good work. I agree with your worldview that our time is here and now.

I've read your blog and the Globe interview, and am writing to join others who admire your clarity, forthrightness, intelligence and commitment. No messing around, no danger of being misunderstood, but always creative, proactive. Yes you have made a huge difference and continue to do so. Equating the hospice model of "person in charge" as REALLY being really in charge (not of her life/health, but at least as determining what is and is not needed from others), is a clear, fresh way to continue your advocacy. Choice should be the model for all health care, & for most education and caregiving. I make exception for some matters involving young children.

BTW, my friend up your way who told me about the article is Marguerite Pfeiffer, ex-wife (now widow, too) of David Pfeiffer. She wants to be remembered to you as impressed with your work and your style. She's in a retirement community in Peabody.

Best wishes in this phase of your life, know you have an admirer and well-wisher in Florida. I'm glad you have family & loved ones all around. I'll keep current with your blog, and will be living on boat this summer. Ciao & Shalom!

Jody Williams



**Judi with  
George Ebert  
and  
David Oaks  
at Highlander**

## **Wood, Jean**

Dearest Judy;

You are one of the main individuals who inspired me to begin the most fascinating journey of my life. The journey of recovery and advocacy for individuals living with a mental health diagnosis. I say living with because the diagnosis is not the only descriptive I have - just for fun I have included my dossier notes so that you may see what an influence you can be I set out to enjoy and accomplish anything I wanted - thanks so much for your inspirations!!

I applaud your wanting to celebrate this chapter! Not many people embrace life as a journey and so as the journey comes to a close your memories and moments shared will be kept precious in our hearts and for all of us in Oklahoma We APPRECIATE YOU VERY MUCH!

The consumers/survivors in Oklahoma developed the first ever standards for consumer involvement and it went national!

All of course thanks to our original trailblazers! YOU! That we have the ability to stand, enjoy inclusion, have strength to challenge status quo and dispel myths.

Bless you,





## **Yanow, Abby**

Judy,

I'll be happy to join in a celebration of your life and your leadership on health advocacy!

Abby

## **Ziegler, Laura**

### **An Anecdote**

In early spring of 1984 another Project Release member encouraged me to attend a conference in New Jersey to observe a more conservative aspect of the mad movement. The conference was under the auspices of the Self Help Clearinghouse. Local activists Joe and Susan Rogers were working on organizing a statewide coalition and took the occasion to schedule a meeting at a nearby church. They invited Judi to speak at the meeting.

Ken Donaldson was a keynote speaker at the conference but otherwise its tone seemed rather regressive. At one point a woman from the Self Help Clearinghouse who was dripping with gold jewelry and condescension was on stage asking people in the audience from various towns to stand up and exclaiming in saccharine infantilizing tones how she was \*so\* proud of them for attending.

When the time came for the organizing meeting I walked over to the church. The building was locked and about seventy-five people were standing outside in the rain. Someone tracked down the minister and discovered he'd been told by an individual from the Self Help Clearinghouse (who was apparently invested in sabotaging any independent organizing) that the space would not be needed. The building was opened and before introducing Judi one of the Rogers explained to us how it came to be locked.

And then Judi began her speech by putting her hands on her hips and saying in a tone which spoke volumes: "Well." And took it from there.



**Judi at the  
Mental Health Consumer  
Conference  
University of Maryland  
1982**





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