

AN EMERGING FORCE

by

**Betty Blaska
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Madison, Wisconsin**

1993

WHAT IT'S LIKE TO BE TREATED LIKE A CMI

At the outset, I'd like to say that if we can be called CMIs--chronically mentally ill--then they, the mental health professionals, can be called MHPs. If we have to be relegated to a three-letter acronym--and stripped of our individuality--then they too can be lumped into one pot. I present a series of vignettes from my history with the mental health system depicting what it feels like to be treated like a CMI. I ask you to imagine what it's like.

You spend the whole first evening and night crying. You don't want to be here. There must be a mistake. Your only previous experience of this was the movie Snake Pit. You're only 18, very young, not yet a CMI. Next day the "staffing" is very intimidating. They laugh at you. You tell them you don't want to stay. They patronize you: "Oh, we think we'll keep you a while." You don't know it yet, but you're on your way to becoming a CMI.

The first time you experience dystonia from the neuroleptics they've given you, you're extremely frightened. Your tongue is rigid and you're unable to control its movements. You rush to the nurse's station and they're all huddled inside the little cage's protective walls. They are puzzled by your presence and greatly inconvenienced by it. You can't speak, yet they wait impatiently for you to tell them what's wrong. And you wonder what's wrong with them. It's not that they don't see. They don't feel. Because you don't count. You're on your way to becoming a CMI.

Your first discharge from the psych ward finds you loaded up on major tranquilizers. Your follow-up therapist sees you for a while and then announces that he won't continue with you unless you come in with your family for family therapy sessions--all 8 of you. But they're scattered all over the state. And they don't want to come in because they hate the shrinks almost as much as you do. They've been belittled, brow beaten, and laughed at by the MHPs. You can't get your family to come in, and so the MHP stops seeing you and stops refilling the drugs. So you go through withdrawal. And end up back on the same psych ward. And they say to you with an accusation: "Why did you

go off your medications?" It's then you realize: You're a CMI.

After the second hospital stay, you're supposed to come up with a new MHP to follow you. So they send you back to the same clinic at Lorch Street.

You enter the room and find two MHPs seated in front of you. You ask questions, and they look at each other and respond to themselves, not to you.

You spend the entire hour having the two shrinks talk to each other, not to you, but about you, in front of you. At the end of an hour of this frustration, they say they have no openings, none in the entire clinic. You wonder why they wasted their time and yours. You wonder who's really crazy--them or you. And so you start to see more clearly: You're a CMI.

Your third hospital stay and one of the MHPs informs you that they've demanded that your parents come in for a session today. And they've replied that they couldn't; it was the first good planting day and your dad was in the fields. They threatened your parents with sending you to Mendota, if they didn't come in. You express indignation at their ultimatum and defend your parents. Your father has to put food on the table for eight people. The MHPs seem alarmed at your defense of your parents. Well, their threat worked, as your parents are there that afternoon. Now the MHPs haughtily announce that they've changed their minds. They're sending you to Mendota anyway. Your defense of your father was an "admission" that you're less important than the rest of your family; your lack of self-esteem is deplorable. They're sending you to Mendota ANYWAY. Your parents discharge you AMA--against medical advice--away from the clutches of this hospital's self-righteous MHPs.

Then you end up in Psychopathic Hospital in Iowa City, Iowa. There they tell you you were misdiagnosed at University Hospitals in Madison. You find out you're not schizophrenic, you're manic depressive. You tell the MHPs in Iowa that Wisconsin sued you for a \$3,366.66 bill. They sent the sheriff after you with a subpoena. Would the Iowa MHPs testify that you'd been misdiagnosed, mistreated--treated with the wrong medications--your symptoms made worse, not better? No, they have a collegial loyalty to each other. Their reputations are on the line. And who are you? Only one little patient, one CMI!

As an inpatient in what's called a "mental institution" you go to something they call OT--occupational therapy. Everything here is called therapy--even when it isn't. And today it's "assertiveness class"! This is a mockery inside a place called a "mental institution." Because here no mental patient is free to assertively choose, refuse, speak, or act. You can't even listen, to each other. Without someone spying, reporting, recording, and charting. And then calling you paranoid if you notice. Or object. And when you refuse an activity or "therapy"--which they tell you is your right--and which they've taught you to do in their "assertiveness class," then they badger you by sending nurse after nurse, attendant after attendant, into your room to remind you that "It's 1:00. Time for OT!" Your refusals mean nothing. They badger you until you either give in and go, or they've frustrated you to tears. And then they can justify calling you by the malignant label they've designated you by. Noncompliant. Passive dependent. Or passive aggressive. Paranoid. Borderline personality disorder. They're all different labels. But they all mean the same thing: you're not really you. You're just a CMI. And this justifies their dehumanization of you.

You've been in and out of the hospital, on and off a cadre of psychoactive drugs. In doses you complain are too high. In combinations you complain are too much. And of course you've lost your job. Who could work amid all this drug experimentation? And the myriad of drug side effects. Nausea, diarrhea, dizziness. Vision so bad you can't cross the street because you can't judge the cars' distance from you. Drug-induced psychosis so bad you can't leave your bed or look out the window for the terror you feel. Low blood pressure so bad you can't stand for very long, and your voice so weak you can't be heard across a telephone wire.

So, you're without a job. And they send you to a place called DVR--Division of Vocational Rehabilitation. They "help" you get a clerical job. Never mind that you don't want to do that kind of work. Never mind that you have a degree--or two. Or that you have dreams. They "help" you get a clerical job because, yes, you've guessed it, you're a CMI. A woman CMI. But the men CMIs are just as lucky. They get to become janitors!

You're depressed. You're feeling suicidal. None of the medications are working. The blackness ushers in suicidal ideation almost without your needing to give any conscious direction to your thoughts. Your thoughts--they're all negative. Trying to steer them into something positive--because they've said cognitive therapy works!--only ends in bringing up something negative along with it. And you catch the negative thought and start over with something new, until it too leapfrogs you into another negative one. It's as if a whole Pandora's box has been opened up in the attic of your mind, only that box is labeled BLACK. And the box labeled WHITE is locked tight, the key thrown away. And you tire of this endless exercise of redirecting the thoughts. Your mind, nerves, and body are so fatigued as it is.

You call a place named "Crisis Intervention Services." The person who answers is brusque, and unkind. She adds more stressors to your already overtaxed nervous system. You don't want to go on with this life. You're told your situation is not serious enough. And besides, she doesn't have time for you. You feel insignificant. You are. You're a CMI. And you're only one CMI of 1,500 CMIs.

You have a cyclical disorder. After the second year at the same job and the second episode, your MHP tells you it'd be better if you worked part time. Now, you're working for the State--and they push accommodating for the handicapped, and you guess you're one of these. And you're working at a Typist classification, for which job sharing and finding another typist to work the other half should be a cinch. But your boss--himself a physician--insists they need ONE FULL-TIME typist. He won't budge. The University Medical School and the Affirmative Action Officer can't make him budge. You're forced out of the job. It's then you're reminded: You're only a CMI.

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losing all your life. It's his word against yours, and you have a psychiatric label. He's the respected professional. You're only a CMI.

What have you learned as a CMI? Abuse. Physical, emotional, spiritual, sexual, financial. Vulnerability. Lack of credibility. Reduced to a three-letter acronym. Denied your own inner convictions. Frustrated. Stigmatized. Always wrong. Put in double binds.

Until today. Today you speak out. Today you reclaim your self. Today you begin to heal, to heal others. Today life begins anew for you and for others whose consciousness you are trying to raise. Today the patient, ex-patient, mental health consumer movement is reclaiming the dignity and power of the CMIs of this world.

--May 1988

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"PREVAIL"-ING OVER IT

At the outset, I'd like to say that if we can be called CMIs--chronically mentally ill--then they, the mental health professionals, can be called MHPs. If we have to be relegated to a three-letter acronym--and stripped of our individuality--then they too can be lumped into one pot. I present a series of vignettes from my history with the mental health system depicting what it feels like to be treated like a CMI. I ask you to imagine what it's like.

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Through PREVAIL--Psychiatric Reform thru Education, Visionary Action, and Intense Lobbying--we are advocating for the rights of those labeled mentally ill. We are educating the public, the media, and those training to become MHPs about how to treat us with care and humanity. We are advocating for choice, control, dignity, and hope.

*D for Depression (1988? 1989?)

DEPRESSION WITH A CAPITAL "D"

Published in Alliance for the Mentally Ill of Dane County, *Pioneer*, 19__

Speech for "Safety in Human Services," MATC, 19__

I'm a manic depressive. And I believe the English language needs another word for "depression." Everyone thinks they know what depression is, since everyone has been depressed at one time or another, right? Your boyfriend leaves you, you've failed an exam. So, you get depressed. And if I tell you I'm depressed, you're likely to ask, "What are you depressed about?"

But if I answer "nothing," you are unwilling to let it go at that. Mine is a depression most people don't understand....

The depression you know about is exogenous, or external, depression that is a reaction to external events or situations, depression over a situation or a loss. My kind of depression is endogenous, or internal, that is, it arises out of internal, biological mechanisms. Once started, the depression is self-sustaining and does not respond to changes in the environment.

These depressions feel very much like a physical illness. In fact, some times I've been coming down with the flu and at first, have mistaken it for the beginning of a depression--the body/mind sensations are so similar. In endogenous depressions, my moods are lowered. My body is fatigued and exhausted. I have no energy, no drives of any kind--with sex, appetite, or work. I experience no pleasure in the usual things I enjoy--everything seems a drag. My sleep is disturbed--insomnia or hypersomnia.

My thoughts seem to revolve around an incessant surging of negative past memories. It's as though the positive experiences of my life aren't available for retrieval at this time. My perceptions of things in my present environment are colored negatively; even on sunny days I see gloom. And I have negative expectations and fears of the future; I can no longer look forward to tomorrow. The blackness ushers in suicidal ideas almost without my needing to give any conscious direction to my thoughts.

I remember one depression in my parents' home where I'd looked up toward one kitchen window and saw my Dad's bottle of pills on the sill, and I

thought: Take them; you would die. So, I looked in the opposite window but saw the barn outside, and thought: There must be rope in the barn; hang yourself to die. I didn't choose to think these thoughts--they entered my mind uninvited and unwanted. It wasn't so much that I felt so miserable that I wanted to end it all as that thoughts of suicide constantly forced their way into my consciousness. And I had to work to survive those thoughts.

For years before I knew my depressions had a name or a treatment, I sensed they were something constitutional, something beyond my control. My mother, exasperated, used to cry at me: "You don't have anything to be depressed about!" This was true--I didn't have anything to be depressed about--that should have been the clue!

For this was not depression with a little "d." This was Depression with a capital "D"--a system malfunction, a lack of lower limits on my mood state. I needed to be treated, not rationally talked out of my reality.

Those of us who suffer from Depressions most need people who will try to understand us and not label us lazy or weak-willed or inferior. When I'm in one of my Depressions, I have a need to confide in someone that I'm down. It helps to have a caring, and a careful, listener. Today, when someone tells me they're depressed, I'm less likely to ask, "What about?" than to say "Oh, I'm sorry. How does it feel? How can I help?" That's what helps me.

The flip side of Depression is mania and hypomania. They can be kind of fun, especially hypomania; however, they're really a mixed blessing. For me, mania and hypomania last too briefly and are always followed by unpleasant Depressions. In hypomania I become hyperactive, hypersexual, overly talkative, over-confident, and extremely elated. I cannot remember being down, and I think I'm the best person around! I think, speak, and act very rapidly and become impatient with how slow the rest of the world is going. I have been known at those times to start finishing other people's sentences for them--not an endearing quality, believe me! And I have experienced such intense mania that it frightens me.

So, I take Etrafon, which is the combination of an antidepressant to work on the Depression and an anti-psychotic to ward off the mania. I must

often adjust the dose up and down according to the timing of my cycles. Yet I work 30 hours per week, take University classes, and am active in the mental health consumer movement. I take sick days when I must, because I see this as a physical illness like any other. But I work harder than most people without my limitations. In fact, Steve Crossan coined a slogan, which we have put on t-shirts: "Hire a Manic, They Work Like Crazy"!

My main plea to mental health professionals--I call them MHPs because if we as CMIs (chronically mentally ill) can be relegated to a three-letter acronym, so can they! My plea is: Do not judge us. Do not malign our character or reject our personalities. We are not manipulative, weak-willed, immoral, unsafe, incompetent, uninteresting, or lazy. But we are sensitive and compassionate, caring and giving. Many of us are quite bright, quite creative, and quite competent. In fact, our strengths are many. We are exceptionally strong and increasingly persevering. We have overcome enormous obstacles: job discrimination, financial hardships, psychiatric, physical, and sexual abuses, psychological oppression, demoralization of our confidence, and the discrediting of our ideas and our intelligence. But we have survived. We have endured. And we will *prevail*.

Bipolar

UNIVERSITY OF WISCONSIN DEPT. OF PSYCHIATRY
MADISON, WISCONSIN
GRAND ROUNDS PRESENTATION

PREVAIL, Inc.

(Psychiatric Reform thru Education, Visionary Action, and Intense Lobbying):

"PSYCH HOSPITALIZATIONS: WHAT HELPS, WHAT DOESN'T"

Introduction: Barb Herman, M.D.:

I'm privileged today to open today's Grand Rounds. The topic is "Psychiatric Hospitalizations: What Helps and What Doesn't." We are fortunate to have four mental health consumers here to share their thoughts and experiences with us, and they would prefer to introduce themselves as they go along.

Betty Blaska:

Hi, I'm Betty Blaska. I'm a twenty-year consumer of mental health services, and I would call myself a psychiatric survivor, but I'm not sure yet if I'm going to survive.

There are two conditions that are key for good interactions between patients and staff. One is to listen to the patient and try to understand him or her in their totality. And that means a minimum of questions and a maximum of listening, silent listening. My doctor looks at me with eyes of intelligence and caring. And he's trying to understand what's going on behind the words I'm saying. In my heart, in my soul, in my head. And the other condition is to be honest in communicating. If these two conditions are met, the patient will trust the professional, the patient will be honest with the professional, and there will be no need for terms like *manipulative*, *noncompliant*, or *borderline*.

There are about four issues I want to touch on. The first is **choice**. I have seen on most psychiatric wards that I've been on that there are always assertiveness training classes. My feeling is that it's a mockery to teach

assertiveness training on a psych ward if you do not expect the patient to use the assertiveness training *on the psych ward*.

I recall incidents where a staff person would come into my room to announce a particular activity, and I would politely say, "No, thank you, I'm not interested today." But they would send in aide after aide, and nurse after nurse into my room to tell me about this particular activity. This would frustrate me to tears. I wish to be respected when I say "No" as much as when I say "Yes."

Another issue has been resting in my room. A lot of times we are discouraged from doing this. I've even seen a patient locked out of his room, which really didn't achieve any purpose, because the patient then looked for a sofa or a floor to lie on. You have to understand: the medications we take are very sedating. Sometimes it's very hard to wake up. On top of that, depression is fatiguing. I've often felt that my head is too heavy to hold up, or that in severe depression, I'm only comfortable in a prone position, for some reason. I'm not sure why, but it's very common with me. And I feel that I need to be respected in the choice that I make about resting in my room or not resting.

A positive example of choice has occurred on my twelfth and current hospitalization [speaker was an inpatient at time of this presentation]. My doctor offered me this choice, and this is the first time it's ever happened: I could go to my staffing for all of it, none of it, or part of it. I immediately elected to go to all of it, and it was great. I didn't have to wonder what was being said behind my back. I was there to correct any errors in the doctor's presentation, and I felt like I was a full part of the treatment team. Not only did I have a voice and a choice in my goals, but it gave me the motivation to try to reach those goals. And the treatment goals should be mine. Especially if I'm a voluntary patient.

On one of my hospitalizations, I was told by a staff member that she was concerned about my obsessiveness with the drugs. Well, I tell you, if you go to my bipolar support group, you'll find that we're all obsessed with the drugs. And whether I want to concern myself with that issue or with

interpersonal functioning or with personality dynamics, or whatever, that should be my choice.

Another issue is the family therapy sessions. I had occasion to be in the planning for a family therapy session, get to the family therapy, and find that the staff members outnumbered the family members, which was very intimidating, both to me and to my family. But worse than that was that as the session went on, I found that my objectives for the session were not being met. The staff had planned their own agenda as to what they wanted to accomplish.

The second issue is **control**. I know that patient generally have a right to see their charts and their records, but I feel that this is not enough. I want to be able to write in an addendum in the chart, sign it, and date it. I have found on the one time that a staff person asked me if I wanted to see my chart, there was a gross error. The incident was that I had left a relaxation exercise, and she wrote that I was upset and crying and fled out of the room, when in reality I was having trouble with my sinuses. I wasn't crying. And I thought if they made this mistake over such a minor incident, what else was in my chart? I really didn't want to know anymore. And it makes me feel powerless to have my behavior analyzed and falsely interpreted by someone else.

On any hospital ward, whether it's psych or whatever, the patient finds the routine is set by the institution, often for the convenience of the staff. But as much as possible, the patient should be given control. This may be with respect to placement of room or choice of roommate, for instance. Often when I've got to the hospital, it was to seek quiet, and I've suffered from hyperacusis--hypersensitivity to noise. For that reason, I've asked my room be away from the music room, because I have no control over piano playing by someone that's manic at the time. But I feel patronized when the request is met with the accusation, "What's the matter? Don't you like music?"

With the roommate situation, a person has even less control. Staff come into the room to speak to your roommate, regardless of time of day, whether you're in the room or not. When the room is dark, the curtain between

the beds is drawn, and I'm trying to sleep, I feel I have the right to ask the visitor to talk in a lower voice than in a booming one. The same if I am talking on the phone. And also, I don't want to hear my roommate's one-on-one with their staff person if I am in the room. Personal histories and treatment should be kept confidential in all respects. Both in all of these instances, I have asserted politely my own needs, and usually been met with silence and noncompliance rather than a respectful apology and consideration.

The third key issue is **dignity**. I remember sitting in a psychiatry lecture hall when I was a student in grad school, and they brought in a woman from the psych ward, and the professor began to question her about her delusions. The students were laughing uproariously. I was suffering from depression at the time, and I sat there crying. Not only for this woman, but also for the medical students, who were not witnessing or modeling compassion or sensitivity.

A positive example of sensitivity concerns some difficulties I had out on pass recently. I was deluged with intense self-destructive fantasies and impulses. I called the hospital and told them I was afraid to come back. I said I didn't want to be thrown into isolation, have my clothes taken away, be thrown on a mattress on the floor, in essence, treated like a dog. The staff were very sensitive, assured me that that wouldn't happen, and urged me to come back. I went, and I felt fortunate because each staff person on the next four shifts treated me with dignity, caring, and gentleness. One woman stroked my arm when I was in the bathroom, cowering with a glass vase, contemplating cutting myself. Others patted me on the back when I was in bed crying and said soothing things while I was so miserable that I couldn't understand how they could even bear to be around me. But they did that for me, and it meant something to me.

A fourth issue is **hope**. I observed a minister come into the lounge area to visit an elderly woman. And as he came in, he noticed this manic patient, who was quite out of control. As he sat down to talk to the elderly woman, he said, pointing to the manic patient, "There's a hopeless case." And my heart dropped, because I knew this elderly woman was very depressed and very

despairing. And sure enough, as he sat down, the elderly woman replied, "I feel like a hopeless case."

Likewise, I recall a nurse commenting to me upon an A.M.A. discharge that I was the "most depressed person" she'd ever seen. I don't feel that we patients can be compared in those ways. And all of these remarks are insensitive. We have all felt hopeless at one time or another. But what we desperately need is hope--or at least to try and believe in someone else who has hope *for us*.

I will sum by up saying this: Please listen with all your heart and being, and not just with your ears. Try to understand my situation and problem in its uniqueness and totality. Please, always attempt to communicate with me and be honest with me, and I *will* do the same for you. If you do not manipulate me, I will not manipulate you. Give me choices as far as possible, and allow me to retain as much control as my safety allows. And please remember, that I am as much a human being as you and deserve the same dignity and respect that I will give you. Thank you.

Barb Hennings:

Hi, my name is Barb Hennings. I feel like I'm at an AA meeting or something. I want to start today talking a little bit just briefly about who I am and what some of my background is. And then I'm going to get more specific and try to address some of the issues that I feel surround the issues of seclusion and restraints and self-destructive behavior. Because that seems to be what affects me the most, and I've had the most experience with. I've been in "the system" since 1965. I can't count how many times I've been in the hospital. I know I've been in Mendota [state of Wisconsin's major mental institution] 37 times. I don't know how many times I've been in the hospital here. I've been in every hospital in town except Parkview, or Parkway, or whatever that new one is that I can't afford. They have seclusion rooms for children there! I've been in hospitals all over the country. Anyway, I've had all sorts of diagnoses, you can guess what the one was for the '80s mostly. It's not my current diagnosis, but I think I've been mistreated as a

"borderline." I've been diagnosed many other things.

So, anyway, I started out my career as a psych patient in a hospital. I spent the years from the time I was 15 until I was 18 almost entirely in the hospital. And at that time they convinced me that it was a good thing to know when you needed help, to ask for help. To be in the hospital was a good thing, you know, when you needed it. It was nothing to be ashamed of, and so, I finally bought that. Somewhere along the line, they changed all the rules.

And now I have to break down the door to get into a hospital, and to beg and plead and grovel--and now, they tell me it's a bad thing. Somewhere in between there, I think, is probably what I think is true.

One other thing that I want to say about myself before we get into this real strongly is that right now I'm having a very particularly bad time in my life. I'm in very bad shape. My son killed himself a year ago this coming Tuesday, and I've been having a lot of trouble because of it. The anniversary has been probably the hardest thing I've ever dealt with. His death has certainly been the hardest thing I've ever dealt with, and yet people ask me, "Well, then, how can you come and talk to a group of people like this? How can you seem so functional, so competent, so okay? And yet you tell us that you're in very bad shape."

And part of what we're talking about here today is what I want to emphasize, people, is that when I tell you I'm in bad shape, I mean it. I don't want to have to prove it to anybody. I don't want to have to convince everybody. My biggest question to people in the psychiatric profession, wherever, whether a nurse of whatever, is why can't you just believe me when I tell you that things are awful?? Put aside whether or not you think I'm manipulating, or whether or not you think that I'm making it up, or catastrophizing, or any or all of those words that you use. I'm in bad shape, and I tell you I'm in bad shape. I would not lie to you, tell you I'm suicidal when I'm not. and I would not tell you that I'm not suicidal when I am. Just believe me, and that's what I want from people. The biggest thing I want from people in the psych profession is to take what I say, that I'm honest, I'm not a manipulator, I'm not trying to get attention.

I just had another friend, about a month and a half ago, kill herself, who had been labeled "borderline," who had been told, you know, that borderlines don't kill themselves, and borderlines are just doing this for attention, and she's just trying to manipulate. Well, she's dead now. She won't manipulate anybody anymore, I believe that.

Anyway, on to what kinds of things happened to me in the hospital. When I go into the hospital, what I'm usually asked to do is make a contract that I won't hurt myself in the hospital. And if I can't do that, I get placed on various levels of suicide precautions and things like that. What I'm told is that if I feel like I'm going to lose control, or I'm going to do something, to go to the staff and tell them. And I try very hard to do that. I'm not always successful, and that creates a whole lot of anger and upset with them.

But what they don't realize is that if I tell them that I feel like I might hurt myself, what they're going to do is take me and put me in seclusion. They're going to take away my clothes. They're going to take away my dignity.

At the very time when I'm loneliest, when I'm feeling the most sad, the most pain, the most need of people. When I want to be held and touched and listened to, they make me go in a room all by myself, and then they start to tell me stories. They tell me, "You can get out when the next shift comes on.

You can get out tomorrow. You can get out when we think you're ready." And when I ask them what that means, they can't tell me. And when the next shift comes, they say, "Well, no, we changed our mind. We're short staffed." Or, "We really don't think you're ready." And so, they lie to me. And they think that I'm too stupid to know that they're lying.

I ask them for things like, for me, when I'm in very much pain, it's very hard for me to just have my mind to occupy me, because my mind does very bad things to me. It tells me over and over and over again how awful I am, how terrible I am, why I should be dead. I need something sometimes to distract that. I can't just concentrate on what's going on in my head. And yet here I am in a room with nothing to distract me. I can't read a newspaper. I can't listen to soft music. I can't talk to someone. I also can't smoke, which happens to be a very big thing for me, because when I'm at

my worst is when I want to smoke the most.

When I'm in seclusion, or on precautions, or whatever, there's a nurse coming every fifteen minutes to check on me and do all this stuff. Where did that nurse go all of a sudden? Why can't she stay, as if she's afraid of me or something? Why can't she sit right outside the door and talk to me? Why can't she play music outside the door? Why do I have to be so totally isolated from people? What happens inside my gut and in my heart at those times is that I think, "I have to be shut away from everyone because I'm so terrible."

And then they come and if I start banging my head on the wall, there's two ways that they usually treat me about that. They either say I'm doing it for attention, which I will do until I lose consciousness--I also have another friend who killed himself by banging himself against the walls of a seclusion room, and he wasn't doing it for attention either--or they will come and put me in restraints. And again, we're back into the whole thing of when will I get out, how do I prove that I'm in good enough shape to get out if people won't listen to me?

People, you don't understand how much control you lose when you're in restraints. People can do anything to you in restraints. you have no control about getting out, except when you try desperately to get out and you succeed, then everybody comes rushing in and jumps on you and yells at you and tells you how awful you are. Which is really wonderful, because you already feel as awful as you possibly can. Anybody who's in restraints feels pretty awful.

So, I think if I can tell you anything today, it's that if I tell you I'm going to hurt myself, believe me. If I tell you that I'm not going to hurt myself, believe me. If I tell you I don't know and that I need your help to stay in control, believe me. And please, don't put me away somewhere in a room all alone. If you feel that I have to be kept somewhere, like in a seclusion room or whatever, because that's the only safe place that you think there is for me at that time, well, then, don't just leave me. I know that there are staffing shortages and all this kind of stuff, but it just seems to me that someone could sit outside and talk to me once in a while. I don't

know what you think I could do with a newspaper. I don't understand yet how I could hurt myself with a newspaper or pages of a paperback book, three at a time, or whatever. But to condemn me to have only my mind and only my feelings for days and days on end is just the most awful nightmare you can imagine, and I really would hope that you wouldn't do that to me anymore. Thank you.

Betty May:

Hi, my name is Betty May. And I've had my illness since 1962. Now, I haven't had it as rough as Betty and Barb, but there's been some pretty detrimental things. And I'd like to try to look at it as though you're trying to do the best job possible. But since I've been in the consumer movement, I've heard some pretty horrifying stories.

I would say mine was in Texas. I must have been very severely depressed, hearing voices, thinking someone was drugging me, cars were following me. I'm totally unaware of any of that because they gave me shock treatment. So, that year, I have no recollection, just bits and pieces from Michigan, when we lived in Michigan, to Texas. They sent me home, they did not even tell me anything about electric shock treatment after I came out of it, that it takes three or four months to recover--I do not know if this is true or not now--no medication.

I was depressed when I went home, and I started hitting my husband's whiskey bottle. And I called the doctor and told him what was going on. He put me on an antipsychotic drug when I was depressed, I found out later. Also, when we moved back to Wisconsin, he told me to stay on the med because my illness could reoccur.

The point I'm trying to get at is: Explain to the consumer when they come in. I was very naive about the whole mental health system when it came to psychiatry. I didn't know what hearing voices meant, I didn't know what was going wrong. And one psychiatrist took the time to talk to me, and I was not assertive at that time. I came from a very detrimental background, and my husband was also a nonperson. so, that shoved more feelings back in me. I

had Dr. Stein [Leonard Stein], with whom you're pretty familiar, for about ten years. I told him about the treatment--sorry to say it was here at University Hospital--and he said what they did was try to provoke me to anger so I'd get these feelings out, and it was the wrong method for me. All it did was shove a lot more garbage into my insides, and I couldn't get it out because I was afraid to speak up.

Medications: I was on Stelazine for ten years. I used to go in and tell them what a rat race I was on. Drinking coffee to stay awake. Tired out. During the majority of this time, I stayed off AFDC. I went out in the working field. They did not know I had a mental illness, and I am proud to say I was asked to stay on every job I wanted to leave. And I made it in management, working 60 hours a week. A lot off tears right now, if I mention that ten years of Stelazine, because it took a lot out of me. They did not tell me any of the side effects. I kept trying to change my mind, change my environment. I'd get belligerent, I'd get angry, I'd get antagonistic, and the majority of it was all due to the Stelazine.

I have been on Navane three years now. Working at a high dosage of 15-20 mg., which was too much for me. I've reduced it through my own teachings, being aware of my body. Dr. Stein had complimented me. So, I am down to between 5 and 7 mg. of Navane. I was on an antidepressant; they finally gave me one after years of being depressed! I'm now off my antidepressant now. So, I'm taking 5 mg. of Navane and just a little bit of Cogentin now and then.

Let the consumer know what these medications do to a person! When they come in and they tell you about these complaints, and your body aches, and you're tired: listen to what they're saying! I feel we can all learn from one another. You can learn from us, and we can learn from you. The doctors and the nurses--and I'm not saying all of you--there's good and bad in every field--you sometimes have to think you're not going to let us tell you what to do, "we know it all." And I'm sorry to have to say that, I don't like to speak that way, but it's been provoking.

Betty spoke on the plan. Let us be part of our plan! And another thing before I close, I'd like to say this: I try to place confidence in doctors

and nurses, but I'm learning to fight back. I'm trying to fight back in a right way and be assertive. When I went to change meds, I went in and told my doctor, and he said, "You've changed so many times." And I really blew. I said, "No, you doctors have changed me. You put me on all sorts of crap in the hospital that didn't work. You sent me out of the hospital more of a basket case than when I went in." So, he changed it. And I think a lot of him.

And another thing I do not believe in. Four years ago I went toxic on lithium. They didn't tell me about that. I called and told them what was going on with me. They in return put me on another damned drug--excuse my terminology--because that was to take the side effects away from the other one. They had me on up to five meds, and I was such a basket case so long that I wasn't really coping, being aware of it, until I called my doctor. First, I called my psychologist, and she called my doctor. And I'll let you know right out what they used for an excuse. I was waiting for my disability after working sixteen years. They said, "We don't think it's the medication; it's because you don't have any money to go anyplace." And I said, "Will you take me off all of it? You put me back on that stuff that isn't any good for me until we find a better solution. At least I'm going to have my mind!"

I've heard of patients being on six, seven, eight, nine, ten drugs. There's one theory I can see: To help the patients or the doctors get a kickback. And it's said, and I don't think it's right. If the doctors would listen to us when we tell them the meds are not working, change the medication, and find one that works, instead of making more of a basket case out of the person than what they already are. That's one of my goals, that I reach out and I tell many other consumers at Support Network [now Yahara House] and different places. Because I just read a good article in *Reader's Digest* that for those who do not think that the doctors are working *with* them, or are working *for* them, go in and have a nice talk with your doctor and share your feelings with him and let him share his feelings with you. Maybe there's a miscommunication, and you'll be able to work it out between you without running from one doctor to the next. Thank you.

Nancy Davis:

I'm curious. How many of you in the audience are from the Department of Psychiatry? [a show of hands] Thank you. Thank you for coming. I really appreciate it. This is a difficult issue, and there aren't any simple answers to it. So, I really am pleased that we have this opportunity to share our stories with you. My intent is not to vent my anger.

I'm a consumer not because I wanted to be. I don't like to be a consumer. I don't want to continue to be a consumer. I don't take medication. I hope never to take medication. And I fight ferociously when I feel that this is imposed upon me. Our stories are somewhat similar, and yet they're dissimilar. The words that sum up my experience in mental and emotional wellness, I could use four words: **control, power, vulnerability,** and **spiritual rape.**

When we were planning our presentation on Monday, Betty, Barb, and myself met with Dr. Diamond [Ronald Diamond], and it was a really interesting planning session. And there was a lot of exchange among us as to what we were going to say today. At the end of this session, Dr. Diamond needed to leave. And he turned to Barbara and said to her, "Barbara, I don't understand what it is you do that gets yourself in the position of being put in isolation. Because I, Dr. Diamond, need to be in control." He walked out of the room, and I felt, "Whoa! In that moment, he said it all." And Barb and Betty and I were there kind of gasping. I didn't have the words to articulate it at the time, but I thought, I'm glad we had that experience, because that's the bottom line.

When I feel vulnerable, vulnerable is capable of being wounded. Open to attack. I am a spiritual human being. I have always been a spiritual human being. God is real to me, and my organizing principle is the law of love. I have dedicated my life to opening up myself for that to be expressed, which means, I am often vulnerable. When I first began to try to articulate who I was as a spiritual human being, I was fumbling around trying to use the language that we share. As a result of trying to articulate that, I was

labeled by my spiritual community, and I was labeled with the "Big S," [schizophrenia] and I was immediately and effectively isolated. I went to the library to look up what this "Big S word" meant. And it meant I was going to become a vegetable, neurologically incapacitated, and there was something in me: my spirit say, "No. No way!"

But it had an effect, that label definitely had an effect. It had an effect in that it had a power. It fed into assumptions. Those assumptions have nothing to do with who I am. All my life I have been therapized and analyzed. And once this label was in place, it did have a sort of self-fulfilling effect on me, and it also seemed in my opinion very self-serving for others.

Five years ago, I decided "Enough!" The point at which I said I've had enough is when I was reading articles in the newspaper from Dr. Marshall, Dr. John Marshall, and other psychiatrists. And I decided at that time I felt I had something to say. so, I went around to the community and said, "This has been my experience. This is what I would like to see happening, and what do you think?" And the feedback was so overwhelmingly positive. I went to bed for a week and pulled the covers over my head. It was too much. One of the persons that I went to was a psychiatrist. And I told him that what I really wanted to address was spiritual experiencing, and he said, "If you talk about the spiritual to the psychiatrists, they won't touch you with a ten-foot pole." And I said, "Thank you so much. I already know that." But it confirmed for me that I really did not want to spend a lot of my time communicating if that was the case.

Within this last five years as I have been addressing this issue and the "Big S word," I have been hospitalized twice against my will. I have had four, what I considered intensely spiritual experiences. Two years ago this November, I was arrested on West Washington Avenue for presumably assaulting two men. I had just returned from Nicaragua, where I had gone down as a personal protest because I wanted to help my neighbor, and at that time two years ago, the whole Nicaraguan situation was quite inflammatory in this country. But I went down to stand with them on that line. I came back. It

had been overwhelming: I came back broken. I came back broken. My soul and my spirit were sick. And trying to assimilate that experience back into this environment was not easy. And I was in the process of doing that this night that I was on West Washington Avenue, so I was brought in involuntarily to University Hospital. And my worst, absolute worst, fear is that I'm going to be ganged up on, overpowered, and have medication forced upon me. I have been hospitalized once before against my will. I never wanted to repeat that situation as long as I lived, but here I was once again.

So, because of this opportunity today, I wanted to try and take that experience and tell you what was good about it, and what wasn't so good about it. What was good about it was the doctor who interviewed me in the E.R. [emergency room], who treated me. I came in in shackles. I had them around my ankles. I had them behind my back. And I had gone through this enough times that it's kind of like a movie that keeps getting played over and over again. This doctor talked to me as a human being. That felt really, really good. I mean, I felt a little compromised with my hands behind my back, but he did talk to me as a human being. And I was put on the ward [psychiatric ward]. And as I say, my worst fear was to be ganged up on and have medications forced on me. The second day I was there, or that night, I don't know, I'm not sure, I fought back. I fight back. And I was put into isolation again, and others have talked about their experience in isolation. I wanted my husband to be there, and he was not allowed.

What was positive about that--I'm getting to the negative first--the positive about that was the psychiatrist who interviewed me and said for me to focus on two things. And he took my head almost and said, "Look at me." Because my husband was with me. And he said, "I want you to focus on sunshine, and I want you to let aliveness sink into you." That felt really good, somehow. There was something positive that I could hand on to. The other things that were positive were after I came out of isolation, the patients in the dayroom asked me how I was. They also asked me if I needed some food. I felt received. I felt received. The other thing that was extremely important was another patient whom I held in my arms one whole day.

I don't know who was comforting whom, but I felt like I was a positive human being. And that was a positive experience. I needed to know that I was in some way positive. One of the most important things that was positive was the psychiatrist who didn't diagnose me. Because he said, "You are a spiritual human being, and we don't know very much about that." Knowing what he didn't know and refusing to put me in a box that he did know. I loved playing ping-pong. I loved playing the piano. I even liked the food.

What was negative? I've mentioned a couple. It was the insisting that I have batteries of tests. The insisting that I continue to articulate who I was in a rational, logical, linear way. I was so physically, emotionally, and intellectually exhausted. But I knew this is what I had to go through in order for me to become credible in your eyes, I felt. Another negative: A doctor telling me I was probably a "borderline personality" and had had a psychotic experience when I had never seen her before.

When the charges were dropped, and the psychiatrist told me that I could leave, I called my husband. And I said, "Come and get me, because I don't believe it." Before he got there, I had doctors and nurses insisting that I could not go because I didn't have a diagnosis, nor had I gone through the prescribed tests. He came, my husband came, and I said, "I'm leaving, but you've got to protect me." And I said, "We'll get to that door, and I bet I won't be able to get out that door." And he said, "No. Of course you will."

I said, "I won't." And I had my hand on the door, and the nurse came and said, "But you can't go." I said, "Yes, I can." And I left.

I've tried to balance the positive with the negative. As I wrote this and have been preparing for this presentation, I have been able to see both sides more clearly, and I said when I started it, it is a difficult situation.

It's a difficult issue. I sincerely felt the staff and the psychiatrists in every situation I have been in have sincerely tried to do the very best that they can do. I think as professionals and consumers we have a lot to say to one another. We have a lot to learn from one another. I think if we can talk, if we can respect one another's integrity, and if we can carefully listen to what each one of us is saying, I think it's be a good working

relationship.

--November 3, 1989

MENTAL HEALTH CONSUMERS: AN EMERGING FORCE

The family advocacy movement, begun formally by the Alliance for the Mentally Ill a few decades ago, became a powerful lobbying group, sometimes in opposition to the psychiatric establishment. The mental health consumer movement is the third great movement within the mental health industry--an emerging force of clients, ex-patients, mental health consumers, and psychiatric survivors who desire an equal representation of our concerns in the mental health equation. We want several things: active participation in our treatment plan; treatments that are voluntary, humane, and compassionate; as much control as our safety allows; dignity as human beings not as "CMIs"; and hope that we can recover, that we can lead better lives.

I subscribe to the concept of lawyer/advocate/consumer Susan Case, who said, "I am the expert on my illness. My psychiatrist and therapist are the consultants I've called in on my case." We consumers know our illness best because we know our bodies. We know when the drug dose seems too low--or too high, as is most often the case. We know how the side effects feel and how much pain we will tolerate. When we refuse a drug, we don't want to be labelled "noncompliant" without first being asked why; I maintain that there is most often a legitimate reason behind our drug refusal.

It was only in 1989, with my 12th psychiatric hospitalization, that I was invited to attend my hospital staffing--all of it--not just the peremptory "introduce the patient and ask her a few questions." This meant I did not have to wonder what was being said behind my back. I could correct factual errors in the medical student's presentation. I could express a choice in treatment options. I was a full partner in the treatment process. Involvement in formulating my treatment goals gave me the motivation to achieve those goals.

Our Madison-based group PREVAIL (Psychiatric Reform thru Education, Visionary Action, and Intense Lobbying) aims to educate consumers to take more control over their lives and to re-educate mental health professionals to make services more responsive to consumer needs. To these ends, we have sponsored

a series of panel presentations of consumers talking to mental health professionals about our mental illnesses and treatment needs. We have held a "Community Medications Group" at the public library, which featured a consumer-friendly psychiatrist fielding questions from consumers and family members. Four of us spoke on "Psychiatric Hospitalization: What Helps, What Doesn't," at Psychiatry Grand Rounds at the University of Wisconsin--Madison Psychiatry Department.

At our 2nd Annual Statewide Wisconsin Consumer Conference, we offered a workshop "Psychiatric Drugs--What You Need to Know." We brought in resources on drugs, drug hazards, lithium toxicity, tardive dyskinesia, poor prescribing practices, a patient-professional collaboration checklist, a patient bill of rights, etc. An educated and empowered consumer is a better patient, and presumably, a healthier one.

Within the consumer movement more strident voices decry use of the term "consumer," as it implies volition, whereas many of us have had little choices open to us in our treatment. It is up to us--the consumers demanding a voice and the professionals listening--to restore to the word "consumer" its true meaning: a person who voluntarily chooses treatment from a variety of options, including self-help and peer support groups.

--November 1989

WHERE IS THE "MOVEMENT" IN THE WISCONSIN CONSUMER MOVEMENT?

There were some 100 mental health consumers, ex-patients, and psychiatric survivors from around Wisconsin who came to the Manitowoc Holiday Inn for the Third Annual Statewide Consumer Conference. They came ostensibly to fight stigma, gain empowerment, learn advocacy, offer support, raise consciousness, and foster change--as these are the goals of the NIMH Consumer Demonstration Grant and the Wisconsin Network of Mental Health Consumers--co-sponsors of the conference along with the State Office of Mental Health and the Wisconsin Coalition for Advocacy.

Nancy is a young woman who's been a psychiatric inmate at a Trempealeau County institution for six years. She never heard of the word "consumer" when her advocate from WCA visited her on Thursday, the second day of the mental health consumer conference. But she's been stuck in surroundings best described as a "hole" for six years, 4 1/2 hours from her county of residence Manitowoc, site of the consumer conference. She could leave the "hole" if there were a group home available for her to move into.

Homes for Independent Living offers a six-bed group home on Hecker Road in Manitowoc for which Nancy has been approved. The Human Services Board approved it by a vote of 7 to 1. Neighbors oppose it for reasons reducible to fear and ignorance of the mentally ill. The County Board must vote on it.

Five of us consumers from Madison sought to take Nancy's fight to the people, to the County Board, and to the press. We came with signs ready to peaceably demonstrate in front of the County Board at the Courthouse. We hurt for Nancy and those other five psychiatric inmates whose lives could be bettered if only the County Board and neighbors would give them a chance, if only they understood that mental illness does not reduce us to helpless children or wildly violent criminals. These six and thousands of others were missing from the ranks of the one hundred conference attenders. We 100 were the fortunate few. But we wanted to lend our voices to those not able to feast of the generous meals and luxurious accommodations of the Manitowoc Holiday Inn--those who were stuck away in dingy and dark prison-like holding

tanks for those society prefers not to see. We were here, but they could not join us in the fight for a better world for all mentally ill.

Tuesday night we five went to Wisconsin leader #1 disgruntled that he had not given us the address of the County Board meeting and that the other movement leaders had left without including us. He told me to "lighten up." Wednesday night we went to Wisconsin leader #2 to garner support for a picket early next morning before breakfast, but she was "busy with the conference and peer counseling." Next we went to out-of-state movement leader #1. She gave us her jaded comment that all her political activism had backfired and resulted in worse outcomes. She told us further that we were as wrong for forcing our views on society as the establishment was in forcing measures on psych patients. She called one of us "Nurse Ratchet" (he was deeply wounded; it was his very first consumer conference, and he was eager and motivated, caring and compassionate). We went to out-of-state movement leader #2. He was sympathetic and "not afraid of confrontation" (though this was to be a peaceable march), but said it should be focused. And he said we should do something positive for the neighborhood; he suggested we take garbage bags and clean up the neighborhood's trash. I responded that the neighborhood of the proposed group home was well-to-do and probably not full of garbage. We went to the WINMEHC membership meeting Wednesday night. "Nurse Ratchet" asked what we were doing for the hospital inpatient consumers. Wisconsin leader #3 said that was WCA's responsibility. He had also said that we were an "outpatient state."

We felt crushed and defeated. We called Nancy's advocate in Madison and told her of our opposition. We told her to tell Nancy we were behind her and that one of us endured name calling for her sake. Thursday morning we went to out-of-state movement leader #3. She was very caring and more sympathetic than the others, but she said we needed to be invited by the community. It was a bleak rainy, windy morning--not an ideal day for a demonstration of our concern and conviction that the psychiatrically imprisoned need a chance to live among us in group homes. Some of us spent the morning driving through Point Beach State Forest. The colors were exquisite. We wondered if Nancy

had had a chance to see beyond bleak colorless walls in her six years of incarceration. We wondered Where is the political movement in the Wisconsin consumer movement? We decided to leave the conference after the 1:30-3:30 workshop.

The workshop was on advocacy and was the first workshop ever given by Dave Sommers and Scott Jerry. It was excellent. They involved our hearts and minds in an interactive and guided way that provided learning and growth. At the end of the role plays a woman stood up and introduced herself as Fran LaVarnway, President of Manitowoc Alliance for the Mentally Ill. She told the audience of the proposed H.I.L. group home's plight. Consumers there rallied in response to Faye's heartfelt plea. Someone suggested inviting a newspaper reporter to the conference to meet us, to see that the mentally ill are not two-headed monsters.

We went to our room excited and alive. We were focused. We were doing something positive. We were invited by the community (AMI President LaVarnway and mental health consumer and Manitowoc resident Joyce Kress). "Nurse Ratchet" felt redeemed. "We're staying," he enthusiastically proclaimed. We made the call to the newspaper, and for the first time that day the sun came out. Carol Curtis of the *Herald* accepted our invitation to meet us before breakfast the next morning, the last day of the conference. That night the five of us listened to consumer Stormy Jackson at the "Speak Out" and were further inspired. She spoke of how she first attended the Chicago NAMI Conference with excitement, only to find few consumers speaking for themselves. She was eager to come to the Manitowoc consumer conference but found it only "a little better." Where were people interested in political change, in bettering psychiatry, in promoting individual choice, in reforming the system? "Nurse Ratchet" responded to her oration, "I'm moved!" And we invited Stormy to the meeting with the reporter.

It was a fun session. It was one of kindred spirit, of shared vision for a better world for Nancy and the other five would-be residents of the H.I.L. group home. Joyce Kress, resident of Manitowoc and member of the Long-Term Support Committee, spoke intelligently of the facts. And she put in a

plug for their newly found support group "Open Door." Stormy compared the opposition to the group home to white neighbors objections to blacks moving in, thus properly contextualizing the mentally ill's struggle as political and as a civil rights movement. We posed in front of our picket signs that read "Stop Stigma," "Replace Myth with Fact," and "Mental Illness Can Happen to Anyone." After noting that the neighbor most opposed to the mentally ill moving in could himself come down with a mental illness some day, we laughed that "we wouldn't hold it against him." We felt better about ourselves and our movement.

Where is the political movement in the Wisconsin consumer movement? It is a fight within the movement as well as without for the dignity and importance of every person ever labeled mentally ill--whether inpatient or outpatient, poor or rich, working or disabled, black, red, or white, gay or straight, physically challenged or not, powerful or weak. It is a fight within our own hearts to muster self-esteem, dignity, and integrity. And I learned a lot at the Third Annual Wisconsin Consumer Conference. I grew in confidence as I found my own inner source of strength to overcome oppression and adversity. And I couldn't have without the support of several other nurturing consumers who believed in themselves and in me, and who believed that the political cause of justice for those labeled mentally ill is bigger than any one of us or any group of leaders.

--December 1990

PEOPLE ARE NOT EXPENDABLE

Recently the Mental Health Center of Dane County issued a letter stating that individuals in four diagnostic categories would not get the treatment they need--long-term psychotherapy--from their agency. They are incest survivors, Borderline Personality Disorder, Multiple Personality Disorder, and eating disorders. It was presumed that most people in these categories were getting services from the private sector. Some are. But those making only \$400-\$500/month, whose Medicare benefits don't cover psychotherapy are going without the critical treatment they need to stay alive, heal, and thrive.

Chapter 51 of Wisconsin Statutes mandates that mental patients receive prompt and appropriate treatment for their mental illnesses. Yet people in these four categories--predominantly women, mainly survivors of childhood abuse--are not getting it. They are being given drug "treatment" and are going in and out of hospitals in acute crisis, or dying by suicide. The courts mandate treatment for incest *perpetrators*, whose rehabilitation rates are low and recidivism rates high. Incest *victims*, however, are often left out, though they *can* be successfully treated, and the costs to them and to the community thereby reduced. Society owes at least as much to these women who were so traumatized as children. Some of us consumers have formed the group PROD--Persons Representing Ostracized Diagnoses--to lobby for these individuals, whose diagnoses Dr. Ron Diamond called "the garbage bag category." Several of us picketed the Mental Health Center and grabbed the attention of the *Capital Times*. I carried the sign "People Are Not Expendable." I and Dianne Greenley of the Wisconsin Coalition for Advocacy have asked David LeCount to convene a task force to study the costs of treating, not treating and potential funding sources, for which we are still waiting. We have written to the Human Services Board and the Adult Community Services Committee. I have brought this issue before the Mental Health Council for its attention. There it did suffer from the stigma associated with incest and from fears of blaming the family (from some AMI folks, who might as well call themselves *AFMI*, for "Alliance for the *Families* of Mentally

Ill). The chair of the Council is, however, educating the members on the issue of child abuse.

The funding can be found. Wisconsin was innovative in seeking funds for the mental health treatment of seriously emotionally disturbed children, who parenthetically are often disturbed because of abuse. We really owe as much to the adult survivors of body-psyche ordeals whose lives are now seriously out of balance.

If you are interested in joining PROD, doing what you can to write letters and lobby, join in a class action suit, whatever, please call or write to me, Betty Blaska at 622 Braxton Place, Madison, 53715, (608) 258-8527. Thanks for your support.

December 4, 1990

PREVAIL: ADVOCACY

Self-help is a valuable adjunct to professional treatment. In fact, I would go so far as to say it is indispensable. Psychiatry is such an inexact science, misdiagnoses and errors in medications so common, abuses still so rampant, that consumers, i.e., someone who "consumes" or uses psychiatric services MUST have access to the kind of empathy, understanding, assistance in advocacy that only the mental health consumer/self-help movement can offer.

Even in 1859 someone, Samuel Smiles, had the wisdom and courage to recognize the importance of self-help. He said:

THE SPIRIT OF SELF-HELP IS THE ROOT OF ALL GENUINE GROWTH IN THE INDIVIDUAL; AND, EXHIBITED IN THE LIVES OF MANY, IT CONSTITUTES THE TRUE SOURCE OF NATIONAL VIGOR AND STRENGTH. HELP FROM WITHOUT IS OFTEN ENFEEBLING IN ITS EFFECTS, BUT HELP FROM WITHIN INVARIABLY INVIGORATES.

(Samuel Smiles, 1859)

PREVAIL was initially just the "Education Committee" formed out of a meeting between Dane County providers and consumers meeting under the chairmanship of David Le Count, Dane County mental health coordinator back in 1988. David has been a great friend to the consumer movement. He continues to meet with consumers/providers every month since 1988 and is intensely dedicated to the concept of self-help and gave us tons of assistance to get the consumer hotline Peer Connection started in Dane County.

But the "Education Committee" was starting to have a life of its own and no longer be just a committee underneath the provider/consumer monthly meetings. So, we searched for a title--and went through some interesting acronyms (like CRAZY: COMRADES REVOLTING AGAINST ZANY YAHOOES!) until we came up with PREVAIL! (And I seem to be the only one that remembers what all it stands for! Psychiatric Reform thru Education, Visionary Action, and Intense Lobbying)

I came into the movement initially believing strongly that *CONSUMERS*

needed to be educated, you know, about their medications, about their diagnoses, etc. But I soon came to believe that it was mental health professionals who needed education as well, *RE-EDUCATION*. About how they can relate better to clients, about teaching empowerment, about misdiagnoses, about mistakes in medication, about being consumer-friendly, etc.

And certainly the public needs to be educated about mental illness and people diagnosed mentally ill; there is so much myth, misconception, and fear.

And the media plays a role in this: they need to be re-educated, too. I feel the media portrays us, and the public thinks of us, in two polar ways: either as a violent, crazy criminal (the homicidal maniac) or as a passive, child-like person who needs to be cared for.

The President of the Dane County AMI, Dr. Beilman, wrote an excellent letter to the editor in *The Capital Times*, for Mental Illness Awareness Week, where he pointed out that the mentally ill, with proper diagnosis and treatment, could live successfully in the community. But that discrimination in housing, employment, and insurance coverage compromised their ability to rebuild their lives. Excellent letter! But the paper put the caption on it:

LET'S TAKE CARE OF THE MENTALLY ILL!! TAKE CARE? *Oh, let's!!!* I wrote that what we want and what Dr. Beilman's letter pointed to was REFORM. Not being taken care of! Would they have said the same thing about Blacks? Or Native Americans? Or gays and lesbians? Let's TAKE CARE of them?

I've brought copies of PREVAIL's flyer. It lists some of our activities held to date. But what is really important, on the second page, is our "Mental Health Consumer Bill of Rights." It is not something PREVAIL wrote, but was given in an address to the Wisconsin Community Support Program staff at a 1988 conference by Colorado Consumer Esso Leete. I've borrowed it from her and given her credit for it. It expresses our philosophy of what we strive for in self- and system-advocacy.

"WE NEED TO BE ACCEPTED AND WELCOMED, RESPECTED AND VALUED AS HUMAN BEINGS." adult human beings - not as dangerous criminals, not as passive, infants

"WE DESERVE TOLERANCE, LOVE, AND HOPE." Matthew told by one doctor he would never work again. Now a foreman - supervises eight men.

"WE HAVE TO SET OUR OWN GOALS." MHPs often set goals lower than what we want for ourselves. - have dreams - MUST hold on to our dreams. knock on one door and find that door locked, knock on another, and another. And if every door seems locked, go to support groups and peer-advocates and get assistance in unlocking the most consumer-friendly doors.

I applied for DVR assistance. closed my case before giving me any services. "too severely disabled"; February 1991. fellow PREVAIL member - UW's McBurney Center for Disabilities scholarship program. We both won \$1,000 scholarships. Now taking graduate classes in social work. Yet only a few months ago I was "too severely disabled" for DVR to rehabilitate me. This is the value of peer advocacy.

"WE MUST LEARN THAT WE CAN CHANGE, WE CAN CONTRIBUTE, WE CAN RECOVER." To be told you will always be mentally ill, you will never recover, you must take drugs the rest of your life--all of these things engender pessimism and despair in the individual. Or to be told, as some have, that you are HOPELESSLY INSANE. I don't believe that! No one is HOPELESS.

AND THAT WE CAN CONTRIBUTE. heightened visibility of consumers in Madison and Dane County. hoping some day the Wisconsin State Journal's "Person of the Week" would be a consumer.

You can read, and I hope you will, all the other points under the Bill of Rights. Esso Leete was very creative in detailing them the way she has. I will just spend a few minutes detailing some of the activities of PREVAIL, and then I want to open it up to questions from you to myself and Deb Brabender, my colleague from PREVAIL, who graciously agreed to accompany me here this weekend.

Again, PREVAIL stands for Psychiatric Reform thru Education, Visionary Action, and Intense Lobbying. And so, I will draw from what each of those nouns in the acronym refer.

"EDUCATIONAL" ACTIVITIES

"Mental Health Month" in May has been a big activity for us in PREVAIL. We

have sponsored **Radio Call-in Programs** on such topics as ECT, psychotropic drugs, and the consumer movement to educate the public about mental health consumerism.

We've held **"Community Medications Groups"** with two very consumer-friendly psychiatrists from the area to answer questions about medications.

And we've worked with M.C. Video Productions, another Dane County consumer group, to do **film presentations** in the public library on issues of relevance to consumers.

One activity last May that I myself am very pleased about and am committed to hold every May is the **Memorial Vigil** for those lost through suicide. It was a candlelight vigil at the State Capitol, with a prayer and open mike for people to remember loved ones. It was a very heartfelt and warm remembrance for those of us not as lucky to survive mental illness and the system. We commemorated all those lost in Dane County for the last ten years--about one/week.

And we've posted our **"Mentally Ill Enrich Our Lives"** posters in Madison city buses throughout May.

The next big educational activity has been our **"Mental Health Awareness" Week**, Rally at the Capitol with Speakers, in the 2nd week in October every year. The first year, 1989 we had a doctor (Dr. Fred Coleman), a lawyer (Tom Dixon from WCA), and a consumer (me)--my father always said "Stay away from doctors and lawyers," and there I was sharing the podium with a doctor AND a lawyer! Two years ago we had Lionel Aldridge. And last year we had Assemblyperson Becky Young, AMI Leader Harriet Shetler, and consumer leader Barb Hennings.

"VISIONARY ACTION" ACTIVITIES

Meeting with the **Employee Assistance Program** members, training them in responding to the needs of the psychiatrically disabled with a long-term goal of decreasing job discrimination and harassment.

And something I think is very needed, a foot in the door of an agency that has not responded well to the psychiatrically disabled in the past is our **Training of Division of Vocational Rehabilitation staff** and discussion of employment needs and accommodations of psychiatrically disabled with DVR. The long-term goal is better service delivery. The mentally ill composed ONE FIFTH of DVR's case load. Yet their rate of successful rehabilitation of us is a dismal 13%. Clearly, more needs to be done.

We also gave a **"Greatest Comeback" award** to the best essays written about coping and overcoming mental illness. A way of encouraging among consumers a VISION of how they can struggle and overcome.

"INTENSIVE LOBBYING" ACTIVITIES

When I had my first psychiatric hospitalizations, 20 years ago, I thought to myself, I'LL BE BACK. I WILL BE BACK. And now in PREVAIL, we have found others with the same dream and sentiment, and we are planning **hospital inpatient support groups**, to conduct support groups for the psychiatrically hospitalized to advocate for their needs as inpatients and bridge the gap to outpatient status and successful return to the community. We've had very good responses from two local hospitals in Madison: Meriter and St. Marys. So this will be getting going in 1992.

Another dream I've had is a publications of a **booklet discussing common rights violations** of inpatients and ways to access help. This would be a collaborative effort with the State of Wisconsin, PREVAIL members and the Wisconsin Coalition for Advocacy.

LIVE TESTIMONY BEFORE
WISCONSIN LEGISLATIVE HEALTH COMMITTEE
ON ASSEMBLY BILL 203

MY NAME IS BETTY BLASKA. I am an expert you haven't heard from yet. I am a mental health consumer; I'm mentally ill. I am a MEMBER of the GOVERNOR'S COUNCIL ON MENTAL HEALTH, active in several mental health CONSUMER OR CLIENT ORGANIZATIONS, and a part-time graduate student in social work at the UW-Madison. I had THREE PSYCH HOSPITALIZATIONS in a year's time wherein I was made worse and not better. I was depressed but MISDIAGNOSED SCHIZOPHRENIC and put on high doses of neuroleptics (a drug whose name means "shaking nerve") which made me more depressed not less and caused serious dystonias and dyskinesia (which are involuntary muscle movements). After I made two suicide attempts, they threatened to send me to Mendota.

Instead my parents took me out of the hospital A.M.A. (AGAINST MEDICAL ADVICE). I WENT TO A NON-PSYCHIATRIC PHYSICIAN at Student Health, told him I was a little depressed and needed Elavil, the only anti-depressant I'd ever heard of, which he gave me. And I felt NORMAL FOR THE FIRST TIME in 6 years of depression. I couldn't have done that if I had been locked up, AN INVOLUNTARY PATIENT.

MY FRIEND DIDN'T HAVE IT SO GOOD. She too suffered from depression, but she also wound up getting treated with drugs for schizophrenia. One day they locked her in seclusion, where she threw her robe sash over a vent and hung herself. HER MOTHER AGONIZES TO THIS DAY when she says that she told her daughter not to fight the doctors and to take the drugs. Now she realizes that she was wrong and her daughter right IN COMPLAINING OF THE NEUROLEPTIC DRUGS.

It is well known that neuroleptics cause such uncomfortable and debilitating effects as AKATHISIA, which means a restlessness in which you can't sit still--I PREFERRED TO BE DEAD THAN TO EXPERIENCE THIS UNBEARABLE AKATHISIA--and did myself attempt suicide because of akathisia. I just got back from a conference in New Mexico where I spoke on Medications Mistakes.

Dr. Liebermann, a respected psychiatrist from UCLA told how a colleague of his experimented with a neuroleptic; he suffered so bad from akathisia, that HE wanted to kill himself and had to quit taking the drug.

The drugs produce other effects: TARDIVE DYSKINESIA, which is an irreversible movement disorder, TARDIVE DYSTONIA, which is painful contractions of the muscles, and the life-threatening NEUROLEPTIC MALIGNANT SYNDROME. These drugs are not benign. Each of you here who would rather see us locked up and drugged against our will should take Mellaril or Thorazine or Prolixin or Haldol in the doses we have had to take to see if you would want your freedom and health so jeopardized.

AND YOU SHOULD HAVE TO SPEND ONE NIGHT IN SECLUSION where you are stripped of your clothes--and your decency--given a mattress on the floor to lie on, and never let out to use a bathroom so you must use the floor like some mongrel dog. I know another man who died in a seclusion room banging his head against the iron door to try to get assistance from the staff.

I wrote two articles about my experiences as a psych patient. One was called "The Myriad Medications Mistakes in Psychiatry" and was published in the American Psychiatric Association's *Hospital & Community Psychiatry* and elsewhere. The other was "What It Feels Like to Be Treated Like a CMI," published by the National Institute of Mental Health in *Schizophrenia Bulletin*. I want to quote from two letters that I got as a result of those articles.

Ms. Blaska, I hear you loud and clear in your Medications Mistakes currently published in AMI of Maryland Newsletter. MY SON SPENT 10 YEARS BECAUSE OF WRONG DIAGNOSIS, and never saw sanity, until a kindly doctor questioned, and within 90 days he saw sanity and now is mentally restored since January 1989 when he went into independent living. I have been my son's friend and advocate for these 15 years and have never shied from battle with the mistakes I know to be mistakes. I've had many bruises and very few wins in doing battle, but I see no other way to go.

Another letter came:

[My parents] had me hospitalized in a private mental hospital. After one week of nightmares, I escaped over their barbed wire fence into freedom feeling like I had escaped over the Berlin Wall.

"ESCAPING OVER THE BERLIN WALL?" IS THAT WHAT LEAVING PSYCHIATRIC TREATMENT FACILITIES SHOULD FEEL LIKE? When a couple of us met with Rep. Medinger and told him our stories, he responded, "YOU MAKE IT SOUND LIKE A PRISON." HONORABLE REPRESENTATIVES, some of us call ourselves ex-inmates instead of ex-patients, because INDEED our psychiatric hospitals ARE like prisons. You have only seen the inside of mental hospitals as honored guests and visitors. YOU NEED TO ENTER ANONYMOUSLY AS A PATIENT AND FIND HOW BADLY YOU CAN BE TREATED.

IN NO OTHER BRANCH OF MEDICINE do we force "treatment" on someone against their will. My parents said long ago that if they ever developed cancer, they would not elect to go through the rigors of chemotherapy; they would rather die naturally. No one could force treatment on them. But you could force treatment on me. You will argue, "but their judgement is not impaired." How do you know? The only difference between my parents refusing treatment for cancer and myself refusing psychiatric treatment is that I have

been labelled mentally ill, they have not. YOU WOULDN'T QUESTION THEIR JUDGEMENT, BUT YOU WOULD CHALLENGE MINE. My civil liberties are compromised; theirs are intact.

An exhaustive study of mental health clients in California found that 47 PERCENT--that's almost half--AVOIDED PSYCHIATRIC TREATMENT BECAUSE OF THE FEAR OF INVOLUNTARY COMMITMENT. And a SUPPORTER OF AB 203 TOLD ME THAT WE NEEDED THIS BILL TO HOLD HOSPITALIZATION over the heads of people so they wouldn't go off their medications. Is that what we want? Mental health treatment to be a WEAPON OVER SOMEONE'S HEAD? Our hospitals are already filled with people who want to be there. Do WISCONSIN TAXPAYERS want to have to build more psychiatric facilities to lock up people who don't want treatment?

TAKE ANYTHING AWAY FROM ME, BUT DON'T TAKE AWAY MY FREE WILL. It's how I survived, LITERALLY survived, a bad psychiatric system. I have often had a torturous existence being processed through the mental health system. But at no time was I ever deemed INCOMPETENT, nor was I COURT-COMMITTED to treatment.

I NEEDED MY FREEDOM to successfully navigate through the mental health system.

I applaud the court decisions that protect the rights of consumers--citizens--TO ACCEPT OR REFUSE MEDICAL INTERVENTIONS, including hospitalizations and psychotropic drugs, if they are COMPETENT TO UNDERSTAND THE INTENDED EFFECTS AND THE ADVANTAGES OR DISADVANTAGES. AB 203 WOULD SERIOUSLY COMPROMISE OUR FREEDOMS AND RIGHTS TO CHOOSE; IT WOULD BE UNCONSTITUTIONAL BECAUSE IT WOULD GUT THE WISCONSIN SUPREME COURT'S JONES DECISION THAT PROTECTS OUR RIGHTS TO CHOOSE AND REFUSE MEDICATIONS AND OTHER TREATMENT.

As long as there is NO CURE FOR PSYCHIATRIC ILLNESS, as long as the BIOLOGICAL THEORIES ARE INEXACT, as long as DRUGS ARE AN INCOMPLETE OR IMPERFECT TREATMENT and CAN MAKE US WORSE AND NOT BETTER, as long as drug PRESCRIBING IS STILL TRIAL AND ERROR, and as long as CLINICIANS CONTINUE TO MAKE MISTAKES in diagnosis and prescribing, we cannot humanely allow forced "treatment" and involuntary commitments.

TO DENY MENTAL HEALTH CONSUMERS PARTICIPATION IN OUR OWN TREATMENT

DECISIONS is to STRIP US OF OUR CIVIL RIGHTS as human beings, as citizens of a PROGRESSIVE AND CIVILIZED SOCIETY, and as adults.

IF YOU DENY US THIS PARTICIPATION IN VOTING FOR AB 203, then you vote TO CONTINUE THE STIGMA ASSOCIATED WITH BEING A "MENTAL PATIENT" and TO KEEP PSYCHIATRY A POLICE FORCE INSTEAD OF AN HONORABLE BRANCH OF MEDICAL SCIENCE.

THANK YOU.

April __, 19--

WE ARE AN EMERGING FORCE WITH THE POWER TO HEAL EACH OTHER

A Speech Given at the Yahara House Wingding

Some of you know me; a lot of you don't. So I'll give you a bit of my history. I WAS 12 YEARS OLD WHEN I CAME HOME FROM SCHOOL and went straight up to my room every night for two weeks straight and cried--WAILED really--until finally my mother came up one night and ASKED ME WHY I WAS CRYING. I said I didn't know. And I didn't. She said, "IF YOU DON'T STOP CRYING, WE'LL HAVE TO TAKE YOU TO A DOCTOR." So, I stopped crying.

I SAW THAT AS A THREAT. I don't know what would have happened if she HAD taken me to a doctor. I don't know what the state of psychiatry was like then. But I continued to be depressed, I JUST STOPPED CRYING. There was my last summer at home when I carried sleeping pills with me all the time. I wanted to think that I could take them. I confessed to a priest in the confessional that I was doing that. He called my parents in to ask them to take me to a Catholic psychiatrist. But Dad said No. My dad had always said, "STAY AWAY FROM DOCTORS AND LAWYERS."

I continued to be depressed--FOR SIX YEARS--until my freshman year in college. That's when I got sent to the UW Psych Ward. I was hospitalized there three times that freshman year. Diagnosed, misdiagnosed--I found out later--schizophrenic and put on neuroleptics Mellaril and Stelazine. I never got better, only worse on the neuroleptics (a name by the way which means "shaking nerve") and even attempted suicide on them. I suffered the common side affect from the anti-psychotics,"akathisia," an unbearable inner restlessness that makes you want to climb the walls.

After the third hospitalization, they threatened my parents that they would send me to Mendota. Well, my parents took me out of the hospital A.M.A. (against medical advice). I was still depressed. SO, I WENT TO A NONPSYCHIATRIC PHYSICIAN AT STUDENT HEALTH, told him I was a little depressed and needed Elavil, the only anti-depressant I'd ever heard of. He gave it to me, and I felt great, normal for the first time in 6 years of depression.

And I got hooked up with Dr. Len Stein at Mental Health Center of Dane

County; he allowed me to titrate the dosages of my medications on my own. And I bought a PDR (Physician's Desk Reference) and read the psychiatric journals. WE HAVE TO TAKE OUR HEALTH BACK INTO OUR OWN HANDS.

And that's what I really encourage consumers to do. To learn about their illness and the drugs they're on and to manage their own mental illness. I didn't always find doctors who wanted me to do that, some of the more authoritarian doctors found me a "problem patient." But I left them in favor of less authoritarian doctors who would allow me that freedom.

I subscribe to the concept of lawyer/advocate Susan Case, who said, "I AM THE EXPERT ON MY ILLNESS. My psychiatrist and therapist are the consultants I've called in on my case." We consumers know our illnesses best because we know our bodies. We know when the drug dose seems too low--or too high, as is often the case. We know how the side effects feel and how much pain we will tolerate. And

I remember a workshop leader at a national consumer conference who said that her illness turned around one day. IT TURNED AROUND WHEN SHE SAW HER PSYCHIATRIST DRIVE BACK FROM LUNCH IN HIS PORSCHE WEARING HIS EXPENSIVE 3-PIECE SUIT, and she then told him, "HEY, YOU WORK FOR ME."

When I was hospitalized a year ago, my doctor invited me to be at my entire staffing, not just the portion where the doctors ask you the questions, and then you leave so they can talk about you behind your back. And when the nurse administrator revised the hospital handbook, she asked for my input. I read the current manual and said, you're missing one important person when you discuss the treatment team. The patient. THE PATIENT IS THE MOST IMPORTANT PERSON IN THE TREATMENT TEAM. THEY REVISED THEIR MANUAL.

HEALING

I've gone off meds maybe half a dozen times in my life. Only to get manic and then suicidally depressed. So, I've always come back to the medications. I remember one of the times I had gone off my medication and gotten manic. I had just recently had the baptism of the holy spirit and was very involved with a prayer group. I was later telling Inez Seibel of this

time, that I had gotten manic and thought I had the power to heal. She looked at me very seriously and said, "Maybe you DO HAVE THE POWER TO HEAL."

And I thought: she might be right. Because I feel that we all have the power to heal. To heal each other. EACH OF US IS OR CAN BE A HEALING INFLUENCE FOR EACH OTHER. IN HOW WE RESPECT EACH OTHER AND LOVE EACH OTHER AND NURTURE EACH OTHER.

I think of the people who early on nurtured me and encouraged me in the mental health consumer movement--Sita Diehl and Inez Seibel--especially. That is the movement, all of us working together at loving and giving. That's healing. AND THAT'S WHAT THE MENTAL HEALTH CONSUMER MOVEMENT REALLY MEANS.

FAMILY

And family is important. Whether it's your family of origin or a new family that you've created for yourself. A loving circle of people, whomever they might be. That's what you have here in Yahara House, a place where family can be, the family of other mental health consumers. Where you are accepted unconditionally for who you are. Respected and encouraged. Encouraged to grow. WE PLACE TOO MANY LIMITATIONS ON OURSELVES IF WE SETTLE FOR LESS JUST BECAUSE WE'RE LABELLED MENTALLY ILL.

And AMI, the Alliance for the Mentally Ill, is a family of friends. The acronym "ami" means literally in French, "friend." They are our friends in how much they love us and heal us. That's the greatest good that they do. More than advocating for more research dollars or better paid psychiatrists or newer medications is the gift of healing love. That they give as family to their children and that you all give to each other day in and day out at Yahara House.

SPIRITUALITY

Getting back to the notion of healing. That brings in spirituality. AND I THINK THE MENTALLY ILL ARE VERY SPIRITUAL. AND VERY CLOSE TO GOD. Some so-called "religious" people may try to say that the mentally ill are possessed. POSSESSED BY THE DEVIL. However, a very close friend of mine

passed along the information that in the Middle Ages the mentally ill were thought to be possessed, NOT BY THE DEVIL, BUT POSSESSED OF GOD.

THE "LOWEST OF THE LOW"

Even in all the depressions that I still have, because I still have them, and sometimes they are very severe, even with all that and with my insecurities and inferiority complex, where I feel I am the lowest thing on earth, I know in my spirit that I AM SPECIAL. I am special to God. WE ALL ARE. THE MENTALLY AND EMOTIONALLY ILL ARE POSSESSED OF GOD AND ARE VERY SPECIAL IN HIS EYES.

This same consumer friend told me "We're the lowest of the low." And he's right in the sense that he told me that. Of all the minority groups, the mentally ill are on the bottom of the heap. We face some of the toughest discrimination and harassment there is. THE POWER OF THE STIGMA AGAINST US IS OFTEN VERY SUBTLE BUT VERY POWERFUL BECAUSE OF ITS SUBTLETY. We're always in danger of losing our basic civil rights. They can lock us up and force treatments on us against our will. They fight about whether they'll pay--OR WHO WILL PAY--for our medical care. Research into our illnesses is sorely underfunded. Professionals in this field are stigmatized and underpaid. In one survey respondents said they would rather sit next to a criminal on the bus than sit next to one of the mentally ill. We're the "lowest of the low." AND YET, we are the CLOSEST to God.

I believe that. We have a spirituality that a lot of people don't have. When we put on the Statewide Consumer Conference in 1989, the most well attended workshop was the one that Nancy Davis and Bruce Perron did on Spirituality. And yet they try to use that against us. A woman told me she was put into seclusion when she asked for a Bible on the psych ward. In a research article they cited a patient's "symptoms" as "praying too much." When a friend and I were preparing to speak to psychiatrists and nurses at Grand Rounds we met a psychiatrist who told my friend, "Don't talk to psychiatrists about the spiritual; they'll shut you out." They can call our visions and insights "hallucinations" or "delusions." And sometimes the drugs they give us threaten to rob us of our spirit and our creativity.

THE BEATITUDES

BUT YOU ONLY HAVE TO READ THE BEATITUDES to know that they're talking about us.

"Blest are the poor in spirit, the reign of God is theirs. Blest too are the sorrowing, they shall be comforted. Blest are the lowly, they shall inherit the land."

You know that's us. We are the poor in spirit, the sorrowing, the lowly.

KEN KESEY

In *Dendron* magazine, a psychiatric survivor newsletter out of Oregon was an interview with Ken Kesey who wrote *One Flew Over the Cuckoo's Nest*. David Oaks asked Kesey: "The psychiatric survivors have very low credibility in our society. Any suggestions for our movement?" Kesey replied:

"I SAW THIS PROGRAM THE OTHER NIGHT ABOUT MARTIN LUTHER KING, AND I SAW THE WAY THAT PEOPLE WERE BEING TRAINED TO SIT DOWN IN MISSISSIPPI IN 1964 AND HOW THEY WERE TRAINED TO COVER THEIR HEADS AND TAKE THE BLOWS. I'M AFRAID I DON'T SEE ANY OTHER WAY OUT. YOU PEOPLE HAVE TO GO AND PROTEST, AND WHEN PEOPLE CONFRONT THEM, THEY HAVE TO BE LIKE GANDHI OR CHRIST OR BUDDHA. . . . SILENCE, SUFFERING AND MERCY--REACHING OUT TO THE OTHER PERSON, HELPING SOMEONE UP--AS LONG AND AS SLOW AS THAT IS, I JUST CAN'T SEE ANY WAY AROUND IT. . . . THE POWERLESS PEOPLE, THE ONLY THING THEY'VE GOT GOING FOR THEM IS SPIRIT, AND HEART, AND MERCY, AND EACH OTHER, AND THAT'S OUR CURRENCY. WE HAVE TO BE ABLE TO REACH ACROSS WITH OUR EYES AND OUR HANDS, EVEN TO PEOPLE WE DON'T LIKE. I DON'T SEE ANY WAY AROUND IT."

That confirms what I have been saying about OUR PEOPLE--we have SPIRIT AND HEART, despite of, or because of, our illnesses.

FINDING GOD

I guess if I hadn't had mental suffering in my life, I wouldn't have found God. I had left the Church not long after getting into college. I had a girlfriend who'd tried for years to convert me. And one day in 1979 after one more broken relationship, I turned to this friend and lamented, "I GUESS THERE'LL NEVER BE A LOVE, A LOVE GREAT ENOUGH FOR ME TO LOVE MYSELF." And she looked directly into my eyes and calmly responded, "Yes. There is. There's Jesus' love." For the very first time in the almost ten years that she'd been trying to convert me, I didn't turn her off. I just thought, "Maybe she's right. She might be right."

And I had nothing to lose. I'd had so many broken relationships. So many depressions. So many hospitalizations. I might as well try Him. And I found myself going back to Mass on Sunday. I read in the Sunday bulletin of a special Life in the Spirit class, and I felt God leading me to go to it. My life changed. The Scriptures came alive to me.

WEAKNESS AND SUFFERING

I didn't stop having depressions. But having Jesus gave me something to lean on and depend on to get through. I thought about Paul, and he became my hero. He had persecuted Christians just as I had put down on Jesus freaks at that time--the 60s. And I thought about Paul's "thorn in the flesh." A WEAKNESS THAT HE ASKED GOD TO REMOVE, but he only got the answer "My strength is sufficient for you, for my grace is made perfect in your weakness."

AND I TRULY THINK THAT PAUL'S WEAKNESS MIGHT HAVE BEEN A MENTAL ILLNESS. For it gives me something to relate to, someone to intercede for me.

And I found Scriptures especially helpful. I've always liked the epistles of Peter. Because he talks about suffering.

FROM 1 Peter 1:6 COMES:

"There is cause for rejoicing here. You may for a time have to

suffer the distress of many trials, but this is so that your faith, WHICH IS MORE PRECIOUS THAN THE PASSING SPLENDOR OF FIRE-TRIED GOLD, may by its genuineness lead to praise, glory, and honor when Jesus Christ appears. Although you have never seen him, you love him, and without seeing you now believe in him, AND REJOICE WITH INEXPRESSIBLE JOY touched with glory because you are achieving faith's goal, your salvation."

The Bible gives us lots of encouraging words for our times of suffering.

"Bow humbly under God's mighty hand, so that in due time he may lift you high. Cast all your cares on him because he cares for you. The God of all grace, who called you to his everlasting glory in Christ, will himself RESTORE, CONFIRM, STRENGTHEN, AND ESTABLISH those who have suffered a little while."

1 Peter 5:6, 10

This passage tells me that those of us burdened--OR BLESSED--with mental illness are indeed His special ones, and that our rewards for our times of pain on earth will be great in heaven.

MY FAVORITE VERSE

And one of my most favorite verses is one that my friend Jeanne who helped convert me gave me one time I was in the hospital.

It's from Jeremiah 29:11-14:

"For I know well the plans I have in mind for you, says the Lord, plans for your welfare, not for woe! plans to give you a future full of hope. WHEN YOU CALL ME, WHEN YOU GO TO PRAY TO ME, I WILL LISTEN TO YOU. WHEN YOU LOOK FOR ME, YOU WILL FIND ME. YES, WHEN YOU SEEK ME WITH ALL YOUR HEART, YOU WILL FIND ME WITH YOU, says the Lord, AND I WILL CHANGE YOUR LOT."

I think He can change our lots. WE can change our lots. The SYSTEM is changing. IT IS BECOMING MORE RESPONSIVE TO OUR NEEDS; THEY ARE HEEDING OUR VOICES.

The family advocacy movement, begun formally by the Alliance of the Mentally Ill a few decades ago, became a powerful lobbying group, sometimes in direct opposition to the psychiatric establishment. The mental health consumer movement is the THIRD great movement within the mental health industry. IT'S AN EMERGING FORCE OF CLIENTS, EX-PATIENTS, EX-INMATES, PSYCHI-ATRIC SURVIVORS WHO DESIRE AN EQUAL REPRESENTATION OF OUR CONCERNS IN THE MENTAL HEALTH EQUATION.

WE WANT SEVERAL THINGS: active participation in our treatment plan; treatments that are voluntary, humane, and compassionate; as much control as our safety allows; dignity as human beings not as "CMIs"; and hope that we can recover, that we can lead better lives.

WE WANT MORE THAN "CONTAINMENT," as my friend called it, more than "MANAGEMENT." WE WANT WHOLENESS. We should not settle for less than wholeness. We should insist that staff working with us not set goals FOR US that are lower than the goals WE SET FOR OURSELVES. WE HAVE A RIGHT TO OUR DREAMS, A RIGHT to want complete health and wholeness.

AS THE THIRD MAJOR FORCE IN THE MENTAL HEALTH ARENA, AS AN EMERGING FORCE, WE CONSUMERS HAVE THE POWER TO MAKE CHANGE, AND IN THE END, TO HEAL OURSELVES, TO HEAL EACH OTHER. IF WE CONTINUE TO CARE FOR EACH OTHER AND WITH EACH OTHER. PLEASE CONTINUE THE GOOD WORK YOU ARE DOING AT YAHARA HOUSE. Thank you very much and God bless you.

--May 9, 1991

TESTIMONY BEFORE THE COMMON COUNCIL ON ECT RESOLUTION

Electroshock is the one psychiatric procedure carrying so much controversy and requiring so many "buts." It should be used as a last resort, *but* it often isn't, and not only that, many doctors think it should be a first-line treatment in depression or a first-choice for anyone so severe as to be hospitalized (example: Dr. Max Fink, ed. Convulsive Therapy Journal). It shouldn't be used for cost containment, *but* it is, when the person's hospital insurance is dwindling they start considering ECT. It shouldn't be a great money-maker for psychiatrists or beleaguered hospitals, *but* it most certainly is.

It should never be forced, *but* in many states forced shock is still legal. It should never be coerced, *but* it often is, with doctors or hospitals posing shock or discharge and with family members allied with the doctors against the patient. It should be investigated for safety by the FDA, *but* it hasn't been even though the mandate was made 10 years ago. The memory loss should return in two to four weeks, *but* too often it never does. People shouldn't lose their learned careers as a result of a course of electroshock, *but* often they do (three members of PREVAIL, all women, have Master's degrees that are useless to us after having received electroshock).

Unilateral ECT should be as effective as bilateral, *but* it isn't, and many doctors will frankly tell you that it isn't. (I had unilateral, didn't get better, assumed there was something wrong with *me*--treatment resistant again--a cruel hoax to blame the patient.) (Today 75% of Users use bilateral exclusively; bilateral causes more memory loss than unilateral--APA ECT Survey.)

Electroshock should be used only when all else fails, *but* they don't try all else. And I'm not talking about acupuncture, holistic medicine, massage, etc., esoteric treatments that may or may not be effective. But why is not psychotherapy tried before ECT?

I was told by my doctor only last week, the reason my illness has been so hard to control with meds is my early childhood trauma experience, the

psychological piece, was never dealt with. \$10,000 for a series of shocks, the hospital stay, the doctor's bill--all this could have bought me a lot of psychotherapy. To say nothing of the shocks I did not need and would have been better off without. I am now back in school trying to get another degree.

--Nov. 5, 1991

SURVIVOR'S SURVEY

Survey Questions: (1) What has been your experience with any of the following problems: incest issues, borderline personality disorder, multiple personality disorder, and eating disorders? (2) What services have you been able to access to help your experience/problem? Were they professional, self-help, county-funded, etc? How have you paid for them? What was particularly useful/not useful to you about the services you received? (3) What further services are needed in your community to help you heal from your experience/problem?

MY STORY: NO WONDER!

Sex: Female

City: Madison

County: Dane

Diagnoses: Schizoid personality (1969)
 Schizophrenic (1969)
 Borderline personality disorder (?)
 Bipolar affective disorder (1970)
 Bipolar affective disorder--rapid cycling (1989)
 Post-traumatic stress disorder--delayed (1990)

I was sexually abused repeatedly by my father's hired hand on the farm when I was five years old. It produced devastating reactions in me then, at puberty when my body was changing from that of a child's to a woman's, during my college years when sexual experimentation and indeed permissiveness (the '60s!) was the norm, and during my 30's and 40's when I finally began to receive treatment. Looking back to the immediate childhood period, I cannot believe no one in my family thought anything was wrong with me--there were so many signs!

I hid all the time. Everywhere. Up in trees, in the bottom of the boat my dad stored in the shed, on the roof of a machine shed by climbing up fifty to 100 feet on the rungs of the silo next to it, way in the back of my parents' bedroom clothes closet behind all the boxes. I was very clingy, dependent, and whiny. I was a poor, finicky eater and was therefore extremely skinny. I slept poorly. I would have nightmares that a man was in my room. Wayne had abused me once in my room, in my little crib (I still had a crib because we were short on beds) while my parents were out and I was sick with the flu. When I started the nuns' Catholic school, I was inwardly frightened and felt isolated. I had bladder and bowel control problems right in the classroom. And episodes of throwing up. I was irritable and high-strung and

didn't do well in school at first (getting mostly C's in grades 1-2), but then went on to do well with the lay teachers and got all A's from then on.

When the abuse was happening and my mother would ask me to go up to the barn to call Wayne in to lunch, I would protest that I didn't want to go (because of what he did to me there). It was out in the open in the barn, and I was always scared someone would come in and see that he was doing this "dirty thing" to me. But when she got impatient with my whining and ordered me to go, I started to suspect that maybe she knew what was happening up there, and that maybe it was *supposed* to happen. Especially, when I'd hear her say at lunchtime, "What is she doing in there so long?" when I was in the bathroom off the kitchen trying to "clean" myself. This caused me to distrust my parents intentions to care for me and protect me, and it made it hard for me to have security about the world.

At puberty the effects were even more pronounced. This is when I date the beginnings of my "illness," my "manic depression." I was depressed from grade seven through to my freshman year at college when University of Wisconsin--Madison Psychiatry misdiagnosed me schizophrenic (I never had hallucinations or delusions!). It started when I came home from school and went straight to my room and wailed. Wailed! For two weeks straight. Until my mother came to my room *finally* and asked me why I was crying. When I said I didn't know, she said, "We'll have to take you to a doctor if you don't stop crying." I stopped crying. I don't know what would have happened to me had I seen a doctor.

Everything associated with my body changing was a crisis for me: first menstruation, growth of hair, shaving my underarms, breast development, acne. I remember asking my mother if I could take my bath with my underpants on! The odd thing is she said yes. Didn't she think that was unusual, such extreme discomfort with one's body?

My parents failed to see any of these signs as indicators of a trauma that might have occurred to me, but instead interpreted them as that I was "goofy." Mom would always be impatient with me, and she clearly preferred my sister, who was more "normal." One day when I was undressing in the closet,

as was my habit, she got infuriated with me and kept slamming the closet door on me, all the while I'm crying--powerless to explain the need I have to hide my body, *to hide my shame*--because basically I didn't understand it either, and that was doubly frustrating and depressing for me.

This went on until I was sixteen or seventeen and started hanging around with some girls from the "non-college track" (I was a top scholar in high school; it was my only outlet; I had virtually no social life and about two dates with boys). I would get a case of beer because my brother made false I.D. cards to buy beer (you had to be 21 to buy it and carry it out then). And we four girls would go bombing around Madison picking up guys. We did a lot of necking and some petting, but I remained a virgin (until I was 19). But I liked getting drunk and would do so usually both Friday and Saturday nights with these girls, just about every weekend that summer. My chums giggled at my first inebriation when I rejoiced about the "release of my hib-itions"! Being drunk was an escape. I felt desirable when drunk.

The school should have known I had problems. I asked to see a Dr. Gibeau that a friend of mine had heard lecture, and he came to our high school to see me weekly. But I would sit there mute, unable to unlock the secrets of the inner despair that I held, for I didn't at the time know the secret of that inner despair. He focused on me as though I were a "behavior problem," not a troubled and deeply wounded individual. Dr. Gibeau asked me to have my parents come in for a session. They flatly refused.

I started carrying sleeping pills around with me in my purse. I liked to think that I could take them all if I wanted to. They were only Sominex, and I didn't know their potency. But this was clearly suicidal ideation. When I confessed doing this to my parish priest in the confessional, he asked me to come in to see him. We had regular visits for counseling. But when he queried whether my low self-confidence had anything to do with the fact that my teeth stuck out a bit in front, I was devastated. My personal appearance was my nemesis. I *believed* I was ugly. And his lack of tact and my supersensitivity caused me to quit seeing him. He then asked me if he could talk to my parents, and I agreed. They saw him. At first my parents weren't

going to discuss it with me. All my mother would tell me was that the priest had requested that they send me to a Catholic psychiatrist for therapy, but that my Dad said "NO." **I do fault them for not getting me early intervention.**

My senior year classmates voted me "Most Intellectual Senior Girl." I declined, but they said it wasn't a thing you could decline, they voted me in.

I protested by wearing pants to the picture taking session (girls couldn't wear slacks to school in 1969). As an aside, I think it interesting to note that I went on to have twenty psych hospitalizations and eight suicide attempts in college and beyond, while the "Most Intellectual Senior Boy" had two or three psych hospitalizations in college and then shot himself to death.

I do fault the school system for paying all their attention to scholarship and athletics and not providing for the well-rounded emotional and social functioning of their students.

In 1969 I started the University of Wisconsin--Madison. I started seeing a student counselor at the University Counseling Service. My only memory of the counseling was the time he put his hand on my knee in a poor effort to express compassion. **I did not perceive compassion from this counselor, only violation of my privacy and re-emphasis of the message that I am a body to be touched at men's initiation.** But after I told him about taking 3 Somnex after coming home from a bar, he panicked, said he was unable to deal with this, and referred me to a monster at Lorch Street Clinic.

The psychologist at Lorch asked a lot of questions in an inquisitorial style. I had a hard time answering them. He insisted on hospitalizing me on the inpatient psych unit, 1B, at UW Hospital. From then on it was more inquisitions, repetitions of the same questions--**though nothing about sexual abuse**--and lock-up on the psych ward. I cried all night--I was only 18--and my only previous experience of this was the movie Snake Pit.

I got no therapy on 1B. They basically told me that they didn't believe in that; they believed in "milieu therapy." Well, how were these others who were also troubled going to help me? The best experience I had was in an "Encounter Group" run by a tape recorder with no professional staff present, interacting with five or six other patients and doing "exercises." And when

the exercise was to write down a secret on a piece of paper, I wrote "I was sexually abused when I was five years old." It was the first time I'd been able to do that in a professional context, though there were no professionals present. I trusted very few of the professionals there. But I could write this down on a piece of paper amidst other patients. One of them read it out loud. Later a male patient privately told me he knew it was me. **Nothing further came of this. No follow-up from a caring professional.**

And then as the weeks grew on staying in this hell hole, I finally attempted suicide. A handful of phenobarbital. For which I was punished by the staff.

The most important thing I learned out of this two-month-long hospital stay and the two further stays a few months later was how to hurt myself. I learned from another female patient about burning oneself. It soothed me. It dampened the inner feelings of anxiety, hatred, and revulsion that early sexual abuse instills. And I got more sophisticated about suicide attempts. I made a second "real" attempt in 1970 when I took about 20 chloral hydrate in my dorm room. I was found and ended up in University Hospital.

Of course they put me on medications after the first suicide attempt. Stelazine and Mellaril. They made me more depressed. They gave me akathisia. Akathisia made me want to kill myself even more strongly.

There were family therapy sessions. But these were hopelessly poorly run, and everyone in my family eventually refused to come any more. And we didn't talk about the past. Everyone felt intimidated by my father. **Nothing came up about my odd behaviors as a child or how they might have been related to some kind of trauma. None of us learned anything from this family "therapy."**

No one wanted to pay for these three hospitalizations in 1969-70. **Student health insurance ran out or didn't pay.** My mother hid the bills she got. Finally, my parents were served with a subpoena, at which time **my Dad refused to pay and told his lawyer that I was no longer a dependent** (even though they were claiming me on their income tax report). Then on June 14, 1973--*my birthday*--I received a subpoena from the sheriff to pay the UW

Hospital bill of \$3,666.66. No one of us ever paid this bill.

After my third hospitalization at University Hospital psych ward, the staff threatened to send me off to Mendota. For the ghastly crime of defending my parents for not dropping everything on the farm and rushing into the hospital on a moment's notice. My parents took me out A.M.A. I tried it for a while on the Stelazine and Mellaril and finally quit taking them, went to Student Health, told the doctor I was "a little depressed and needed Elavil." He gave it to me and I felt "normal" for the first time in six years. [Later a different doctor switched the Elavil to Etrafon (an addition of perphenazine to the Elavil, because I was manic on the Elavil alone.)]

I continued well for the next three years on the Etrafon. And did well mood wise, academically, and socially. But my sexual functioning was hampered by my earlier childhood abuse. I had low self-esteem, great longings to experience real love (which was absent in my home), and searched for it through casual sexual affairs with many different men. I continued to drink moderately socially and was really not comfortable socially unless I was drinking. I never married or had children. When I went off the Etrafon, my problems with mood swings began all over again. Besides those three psych hospitalizations in 1969-70, I had seventeen more psych hospitalizations from 1973 to the present. I made approximately eight suicide attempts. I burned myself on some occasions. But I never got therapy for the abuse.

In 1985 at University Hospital I had an unfortunate experience with a male nurse on the UW psych ward. I was in an occupational therapy "Shiatsu massage class," wherein this nurse asked me to be his partner. When it was his turn to apply the massage to me, through fingertip touch to the correct pressure points, he touched me with whole hand, and at inappropriate places. I was confused by this, but buried it. When I brought it up to my psychiatrist a few months later and tried to "deal" with it, I experienced an onslaught of my former childhood abuse reactions: hiding, wailing, increased depression, self-harm, suicidality, etc. I filed a grievance with the Department of Regulation and Licensing. The complaint examiner was sensitive and kind (even though the experience was terribly brutal in its power to evoke

further depression), and she was aghast when she found out I was a childhood sexual abuse survivor. But the Department ruled against me. I got transcripts of the testimony. The male nurse and the head nurse lied throughout. And I was discredited. It was said that I had a "borderline personality disorder," that I lied, and that as part of my "disorder," I put people in no-win situations. None of my long-term outpatient psychiatrists had ever given me the diagnosis borderline personality disorder, only *that* hospital where *that* man victimized me.

At one point with a particular consulting psychiatrist (1985, 16 years after my first entering the world of psychiatry), this doctor asked me "Do you think the childhood sexual abuse caused your illness?" I wondered to myself "What's the right answer? I don't know." I replied "No." And he answered "I don't think so either." [Now I'm re-examining the "truth" of that answer.] With a different psychiatrist in 1988, I asked, "Shouldn't I be getting counseling for the childhood sexual abuse?" His reply was: "You'd have to come in 3 or 4 times a week, it'd cost you a lot of money, and it'd make you worse."

Dr. Coleman was the first psychiatrist to consider psychotherapy for the abuse. I paid for it through private insurance, Medicare, write-offs. I insisted on being whole, despite the fact that the therapy for abuse could not be regular and ongoing but had to be sandwiched in between poor functioning on the medications and entailed more psych hospitalizations and more occasions of self-harm.

I entered a group for incest survivors through Rape Crisis Center [no cost]. I learned some from it, but it was basically a bad experience, as **the group therapist had biases against and stereotypes about "mental health consumers,"** the fact that I was on medications and hospitalized through part of the group experience. But the Rape Crisis Center Crisis Phone Line was and is excellent. Many times they have come to my rescue, even in the middle of the night. Their phone counselors seem quite well trained and very caring. And at no cost! But after the miserable group experience, I sought out Oasis. I'd heard excellent things about their groups for incest survivors. But they

refused me and never answered my question as to why they had.

I entered therapy for the childhood sexual abuse intensely in the fall of '91. That season was marked by acute anxiety attacks, excruciating flashbacks in which I relived the actual details of sexual abuse, terrible depressions, and suicidal ideation. A horrible instance of self-abuse occasioned another hospitalization. (The staff at Meriter Hospital had been the first to ask on intake about sexual abuse.) It was during that hospitalization that I had the flashback and body memory that my father had also sexually abused me: at age twelve. This knowledge devastated me. I stayed in my hospital room in my bed for 24 hours. I did not eat for five days. But I began to realize: no wonder I came home from school every day at age 12 and went straight to my bedroom wailing! No wonder my parents were so uncooperative with the school psychologist and our parish priest! No wonder our family therapy sessions were so dismal!

I am not healed yet. After recalling the body memory and flashbacks of my own father abusing me, I could not continue with the therapy. Succeeding flashbacks, a confused mixture of pain and pleasure, were beyond my endurance. I went through many medication changes. My healing came to a stalemate.

What has been essential to my treatment? The skill, caring, and accessibility of my therapist Dr. Coleman. The excellent support of the staff at Meriter Hospital. The availability of well-trained and empathic crisis workers on the Rape Crisis Center Phone Line.

What else is needed? A wider variety of group experiences for incest survivors. Group therapists [and individual therapists] who are not biased against us mental health consumers, but understand the interplay of a psychiatric disability with an abuse experience. Crisis homes for short-term emergency stays in lieu of psychiatric hospitalization (I have had eight psych hospitalizations since entering abuse therapy). Psychiatric hospitalizations are often experienced by childhood sexual abuse victims as re-victimizing because of the disempowerment inherent in a hospital setting and in treatment by a predominantly male psychiatric establishment. Also needed are routine and sensitive questioning about earlier childhood sexual, physical, and

emotional abuse upon intake at every hospital and treatment facility in the state, with appropriate referrals made to treatment. Better insurance and Medical Assistance coverage for psychotherapy (I am paying \$150 monthly to keep insurance coverage, and paying this on a very low SSDI income). An overhaul of the Department of Regulation and Licensing so that cases are prosecuted more fairly, so that investigators are re-educated that a psychiatric diagnosis does not equate with "liar." Services for victims of therapist/professional abuse because childhood sexual abuse victims are so frequently re-victimized by their "treaters." Re-education of professionals that post-incest trauma does not equate with "borderline personality disorder" (see Gelinas, "The persisting negative effects of incest," *Psychiatry*, Vol. 46, Nov. 1983, pp. 312-332). A new diagnostic schema for post-incest abuse trauma based perhaps on Finkelhor's "Traumagenic Dynamics Model" (see Finkelhor, *A Sourcebook on Child Sexual Abuse*, Sage Publications, 1990, pp. 180-198) and incorporation of this into the American Psychiatric Association's DSM (Diagnostic and Statistical Manual).

Addendum

I had not told anyone in the family about the abuse by the hired man until I was 21 and Mom came to visit me in the psych ward in Iowa City. She told me not to tell Dad. But after she was gone I still felt the need to appeal to Jerome, to somehow make him understand my "mental illness." I thought if he could not accept that I had a biological disorder called bipolar affective disorder, he might be able to understand and accept that serious childhood sexual abuse had caused my mental and emotional suffering all my life. That's why I wrote him the long letter about Wayne, which I mailed in October 1989. He never replied. And everytime I called him, it was obvious he was in a hurry to get off the phone with me. He didn't want to discuss the letter.

In February of 1990, I decided to face the issue head on and called Jerome to discuss the letter. I called at 10:00 pm, and he was watching the news and said he'd return the call. Waiting from 10 pm until 10:30 pm, I

experienced the first panic attack I had had in years on the medication I was currently taking. It was as if my brain were saying "ALERT! ALERT!"

Up until that time I had not had any suspicions that Jerome had sexually abused me--except, except for one shred of evidence. When I was younger, I would wake up in the morning with my pajama bottoms off. Several times. This was very unusual, because it was not something I would have done during the night given my extreme modesty about my body and discomfort with it. (Some years later, I asked Janey if this had ever happened to her, and she said it had.) And when I was trying to understand the effects of my abuse I was reading everything I could get my hands on. And some of the books discussing incestuous families sounded exceptionally like my own. Jerome the tyrant. Mother the weaker, subjugated, tired and worn out wife and mother, unable to cope.

The man who returned my call at 10:30 pm February 7, 1992 was not a man who had just found out his first daughter had been sexually abused repeatedly by his own employee. He was not kind or sympathetic or sorry or upset. He was not even indifferent. He was *belligerent!!* *With me!* When I asked if he'd gotten my letter, his tone of voice changed completely from one of fatherly interest to adversarily: PROBABLY!! And did you read it? "No, I didn't read the whole thing. It wasn't the type of thing that interested me."

He said that Wayne was probably "a fine man in his community" and that this kind of thing "happens all the time, every day, to thousands of girls, and will till the end of time." I experienced a growing sense of alarm. He didn't care. My father didn't care that a man had abused a five year old baby, his baby, *me*.

Where was the man that was thoughtful and somber and concerned when I had tearfully told him about the male nurse at University psych ward in 1985?

Did his outrage then have to do with the fact that this was psychiatry, and he hated psychiatry? But children were rightful territory of their parents, property?

He was accusatory: "What secret are you trying to learn?" "What are you trying to uncover?" "What do you want people to admit?" "Is it going to

help if people admit and apologize?" I was beginning to panic. Had he abused me too? And when he said that "all kinds of things happened to me in my life," I countered with, "But what if they happen to you as a *child*?" And his response was that they did happen to him as a child. I thought, "Oh, no, had he been abused some way in his family." Perpetrators were often abused themselves as children. Is that why Burdette referred to Grandpa in talking to Rich as "that man," that she couldn't stand to be around "that man," and Lila refused to ever visit Billy in the old place "because of the things that happened in that house"?

I didn't know, don't know, the answer to these questions. But that was the worst phone conversation I'd ever experienced. I wished at the time and now to have it on tape so people would believe what to me is so unbelievable.

I got off the phone and sank down into my bed crying, "I don't want that man for my father." I believed I had the emotional evidence then that he too must have abused me.

That week I experienced panic attacks pretty regularly, swings into mania and extreme depression, depersonalization, and an episode of dissociation during a date that left me shattered.

But it wasn't until the fall of 1991 that I was involved in pretty regular intense therapy sessions with Fred Coleman for the childhood sexual abuse because finally my moods had become better with a better balance of medications. That fall I was in school taking five graduate credits, and when the abuse issues started surfacing in therapy, I started going through hell again. Nervousness around men, especially in authority, like my therapist or the professor in my class, because they were men, that I would suddenly become aware of the face that they had a penis. Painful sensations in my genitals during therapy or other times of stress. Reliving the sexual abuse, or "flashbacks." Reexperiencing parts of the abuse previously hidden to my awareness, or new "body memories." Panic and anxiety attacks. Intense depression. Heightened emotionality such that I couldn't watch intense movies and often ran out of movies, especially when they contained scenes of abuse--spousal, parental, etc.

[I'm having a hard time writing this right now.]

Then there was the fateful day in November 1991 the week before Thanksgiving when I had my nephew Max over to watch a movie with me. The choice of movie was not good: "Misery." I started experiencing the genital pains. This mystified me. I was with my 15-year-old nephew; why should this be a threatening situation? Several times throughout the course of the movie Max asked me if I was sick. And repeatedly I said no. He saw and knew it before I did. I kept answering with things like "my head hurts," "this headband is too tight," "I'll take an aspirin," etc. But the movie was full of themes of abuse and infliction of pain and scenes of burning and burning a woman's dress and crosses. When Lisa came to pick up Max, I was never more anxious for them to leave. I received six flashbacks that day and a new memory. I became obsessed with crosses and burning and sacrifice and pain. And I wanted to...I can't tell you what I wanted to do to myself, what I did do to myself the following day after seeing my therapist. But it was a form of acute self-harm, and I ended up in the hospital.

I was there a few weeks, when on Sunday, December 8, I met Max at Canterbury Books to spend the afternoon together. Again a panic attack and the genital sensations of pain. To make a long story short, when I returned to the hospital, I lay on my hospital bed in some distress and started to experience a flashback. This time I was not five; I was about 12, maybe 11. And I saw JEROME, and his genitals. He always walked the halls of the upstairs with a t-shirt on and nothing else. And they were scary to me. And ugly. And I saw this this evening in the hospital. And I called the desk several times in panic. Finally, they sent a nurse to my room. But she sat on my bed. I was moaning and crying, and so she put her hand on my foot. But as she touched my foot, I felt his penis go into me. I FELT HIS PENIS GO INTO ME. I started sobbing, and the nurse flew out of the room to get my primary nurse. I was devastated.

The staff were not that helpful to me that night, and I was going to pack my bags and go home--and kill myself. Except for the intervention of my roommate, also a survivor, who helped me through the night by suggesting we

tear up magazines to let out rage. I tore up magazine after magazine and let out rage. Against Jerome, the staff, all men. Exhausted after an hour and shreds of magazines all over the dining room floor (this at 12:00 a.m.), I went back to my room. A nurse followed me and wanted us to come back and clean up the mess. I said, "No. I don't work here. That was therapy." My roommate was nervous and thought maybe we should clean it up. I said "No. I won't. You can do what you want. But I was a little girl when my father abused me sexually. I was a little girl when I begged the staff for help and they weren't there for me. If I go back in there on my hands and knees and pick up the paper, I'll be a little girl who's being punished, and that will have undone all the therapy the magazine-ripping had accomplished in the first place." She understood. And agreed. The following morning, before the cleaning staff were on the ward, the area had been cleaned up. So, my roommate told me. As I said, I spent the next 24 hours in bed. And the next five days not eating. I don't know why. I just didn't feel like it. Part of it had to do with the fact that it was Jerome who helped bring me into the world. And now I see that he who gave life to me had done that to me, had sexually abused me.

After leaving the hospital I continued to have flashbacks of Jerome abusing me. One in particular was so mixed with pain and pleasure of the sexual stimulation that I found myself vocalizing strange utterances on my bed in my room as it happened to me. And I thought to myself, "how titillating for a 40-year-old man to hear this from a 12-year-old girl!" But Fred said, "No, he was probably too intoxicated to even be aware of the effects it had on you." I had a hard time, do have a hard time, believing my own father, any father, would abuse his daughter. Until I had yet another flashback, and that it was undeniable. I now had the physical evidence. The body remembers what the mind was too traumatized to remember. It was all coming out now. Sometimes I would try not to believe it, and say, I need another flashback to experience it *again* to really be able to believe it. But I would have another flashback, and then I would not want any more flashbacks. *I had to believe it!* Enough was enough.

I had three more hospitalizations in the ensuing five months. During one of them a therapist asserted that if Jerome were an alcoholic he could probably have blacked out and not had memory of the abuse he inflicted on me.

And yet how would you explain his outright belligerence and anger at me during my phone conversation with him about Wayne if he was not at some level "remembering" his own acts of perpetration? And I asked Fred, how could my father be abusing me in the night and I not remember it the following morning?

His answer was that the pain was so traumatic that the mind blocked it entirely, explaining the amnesia that was only now unlocked. And yet I was returning home from school crying, sobbing, WAILING uncontrollably for two weeks straight when I was in 7th grade. And although I couldn't tell Mother why I was crying at the time, maybe I was "remembering" the abuse.

Fred will tell you that I have two disorders: a bipolar affective disorder and post-traumatic stress disorder from the experiences of childhood sexual abuse at ages five and twelve. Maybe he is right. But I have always dated my bipolar affective disorder at age twelve when the depressions and uncontrollable crying started. But that too is the age at which Jerome was abusing me. The *Harvard Mental Health Letter* cites studies proving that in children who just view violence, it changes their brain chemistry. Couldn't the abuse have caused the depressions, caused the change in brain chemistry (heaven knows, I viewed enough physical violence in the home, let alone experienced the violence of sexual abuse). Fred is the expert and he says childhood trauma doesn't cause bipolar affective disorder, but since no one really knows what *does* cause it except to say "genes," I think the jury is still out.

--July 10, 1992

MENTAL ILLNESS AWARENESS WEEK RALLY 1992

THE HOPE LIES IN THE MALADJUSTED

Last year at our 1991 Mental Health Awareness Week Rally Keynote Speaker Consumer Leader Barbara Hennings lamented the fact that the Ten Percent Society--gays and lesbians--attracted 4,000 people to their rally at these Capitol Steps, while we mental health consumers, persons with mental illnesses, spoke to a rally of only a couple hundred.

And yet we mentally ill make up **20 percent** of our society's population, not 10 percent. The National Institute of Mental Health estimates that **1 in 5 persons** will exhibit mental suffering some time in their lifetime.

Yet, I want to tell those of you out there who are experiencing mental or emotional suffering, that though few in number, **you are not alone**. For each one of you who braved to come here, you represent **hundreds** elsewhere. You represent the mentally ill who are too sick to leave their homes, or even get out of their beds. You represent the mentally ill who are hospitalized or imprisoned in confining state institutions. You represent the thousands who have found no choice but to accept suicide. And I, from the bottom of my heart, thank you for coming.

And for those of you who here who are lawmakers, policymakers, MHPs (mental health professionals), family members, and interested public, I want to tell you: **we are not going away. This is 1992. And we are only beginning to speak out. You will hear more from us.**

We who are mentally ill are a minority of 20 percent. But we are not only a minority of the disabled. We are a political minority, an economic minority, a social minority. We experience discrimination in mental health service system delivery, in employment, in housing options, in insurance reimbursement, in rehabilitation choices. In the prejudice and stigma with which other people--friends, family, co-workers, the media, the public--look at us, **and look away from us.**

And yet we are a minority that represents **all** minorities. We are poor.

We are Black, Native American, Chicano, Jew. We are homosexual. We are women. We are physically disabled too. And yet we are, of all the minorities, the lowest of the low, as my consumer friend Dexter Gillett likes to put it. A survey found that of all so-called undesirables, the mentally ill were the **last individuals** a person would choose to have to sit next to on a city bus.

But I tell you we are a strong people. We are intelligent, we are persevering. We are creative. We are spiritual. We are deeply God-fearing and respecting. We are proud. We have heart and soul and spirit. And **you will not crush us.**

To put this into context, I want to read to you a quotation that I keep in my billfold, that we printed some time back in the consumer newsletter *Lighthouse*. It is by the great Martin Luther King, Jr., a Black civil rights activist. But his words run equally true for us mental health consumer activists here today. I will read it slowly and carefully, as I want you to draw in each word:

TODAY, PSYCHOLOGISTS HAVE A FAVORITE WORD, AND THAT WORD IS **MALADJUSTED**. I TELL YOU TODAY THAT THERE ARE SOME THINGS IN OUR SOCIAL SYSTEM TO WHICH I AM PROUD TO BE MALADJUSTED. I SHALL NEVER BE ADJUSTED TO LYNCH MOBS, SEGREGATION, ECONOMIC INEQUALITIES, "THE MADNESS OF MILITARISM," AND SELF-DEFEATING PHYSICAL VIOLENCE. THE SALVATION OF THE WORLD LIES IN THE MALADJUSTED.

That was spoken over 30 years ago, but it is still true today. And its essence is true for us mental health consumer activists. We are used to being called **maladjusted**. We've heard that word, and worse words, most of our lives.

But I want to say this. I too am proud to be maladjusted.

I will never be adjusted to demeaning, dehumanizing, uncaring, brusque, unkind, insensitive remarks by MHPs (mental health professionals) when we

human beings are vulnerable and in crisis. **Will you ever be adjusted to this?**

I will never be adjusted to consumers trying to build a relationship with a psychiatrist or other MHP, only to have that person replaced with a new psychiatrist six months down the line. Or with having to call all over town, all over a city like Madison known for having fine psychiatrists, but being told "We aren't Medicare-eligible. We don't take Medical Assistance. We're not taking any new patients." The good psychiatrists are there, but they are few and far between. **Will you ever be adjusted to this?**

I will never be adjusted to a psychiatric system or a public view that puts psychiatric diagnoses on a hierarchy and decides some illnesses are more worthy of treatment or more needy of dollars than others. I will never be adjusted to the community mental health center's decision to deny long-term psychotherapy, the needed and correct treatment, to those human beings who have gotten the diagnoses borderline personality disorder, multiple personality disorder, eating disorders, and incest issues. **Will you ever be adjusted to this?**

I will never be adjusted to revictimizing treatment within our mental health settings and hospitals--hospital, a word that used to mean asylum, or safe haven--but now means "prison" to so many. I will never be adjusted to lock-ups and body searches, to isolation and seclusion rooms, to four-point restraints. **Will you ever be adjusted to this?**

I will never be adjusted to human beings trying to live on \$400 to \$500 a month where 40 or 50 percent of that is going to pay for rent. I will never be adjusted to public housing that is infested with cockroaches and mice and where the mentally ill are told they are driving out the other residents. **Will you ever be adjusted to this?**

I will never be adjusted to forced medication, forced or coerced electroshock, incomplete or inaccurate electroshock consent forms. I will never be adjusted to the loss of my memory and learning skills from the electroshock I endured or to seeing new friends becoming confused, disoriented, and memory impaired from repeated electroshock and maintenance electroshock. I will never be adjusted to debilitating side effects from

medications. Or seeing my friends develop irreversible brain diseases called tardive dyskinesia or tardive dystonia from the neuroleptics they've endured for years. **Will you ever be adjusted to this?**

I will never, **I will never**, be adjusted to seeing my consumer friends choose suicide or attempt it. As my one-time picket sign said, "NO PEOPLE ARE EXPENDABLE." The loss of one of us is a wound to all of us. Suicide must be reduced, but it is increasing in Dane County, and it is increasing in teenagers across the country. **Will you ever be adjusted to this?**

I will never be adjusted to the squandering of great human talent and potential of human beings who happen to have great emotional suffering but want an identity, a work identity, a dream, a goal, but are told by the Division of Vocational Rehabilitation that they are too severely disabled. **Will you ever be adjusted to this?**

I will never be adjusted to an insurance reimbursement system that equates those of us with mental and emotional suffering as second class citizens and sees us as drains on the system and compares us negatively and discriminatively with the so-called purely "physical" illnesses. **Will you ever be adjusted to this?**

I will never be adjusted to a work ethic that views us as "lazy" or "malingering" when we ask for part-time employment, afternoon hours, time off for therapy appointments, and the rightful accommodations we need to keep ourselves on the job and paying our way in society. **Will you ever be adjusted to this?**

The name of my organization, one of the organizations sponsoring this rally along with the Alliance for the Mentally Ill, is PREVAIL. It stands for Psychiatric Reform thru Education, Visionary Action, and Intense Lobbying. But we like the acronym, which is easier to remember: PREVAIL. Because despite all our adversities--both from within our psyches and from without, from our environments--we have managed, we keep managing, to PREVAIL.

And I will repeat Martin Luther King, Jr.'s words: I TELL YOU TODAY THAT THERE ARE SOME THINGS IN OUR SOCIAL SYSTEM TO WHICH I AM PROUD TO BE MALADJUSTED.

And we maladjusted will continue to speak out, to dissent, to picket, to write letters to the editor, to issue newsletters, to organize, to put our votes in the ballot box, and to PREVAIL. Thank you and God bless you in our struggle.

--October 7, 1992

MENTAL ILLNESS AWARENESS WEEK 1992

"FAITH IN THE LIVES OF THE MENTALLY ILL"

I am honored to address this panel and this audience on a topic dear to my heart: the place of faith and religion in the lives of the mentally ill.

Two years ago when I was a speaker at a Pharmacy Conference in New Mexico, they had a Chicano-Indian nurse practitioner named Elena Avila speak on Curanderismo and Psychiatry. Curanderismo is basically an old Native American religious healing work. She talked about using prayer and incense and ritual in her work with the mentally ill. And she asked the audience why the mentally ill responded so wonderfully to her approach. I was the only mental health consumer in the audience, but only I had the correct answer to her question. I said: **Because the mentally ill are so spiritual.**

Three years ago, four of us mental health consumers from PREVAIL spoke to the University of Wisconsin--Psychiatry Department Grand Rounds on psychiatric hospitalizations. One of us who spoke, a very spiritual woman, was warned by a well-meaning woman psychiatrist: **Don't talk to the psychiatrists about the spirit; they won't hear you.** I'm glad to say my friend ignored this psychiatrist's advice and talked about the spiritual anyway.

One year ago, PREVAIL sponsored its first "Greatest Comeback" Essay Contest to encourage consumers to write on their experiences with mental illness and on how they have overcome. I was so gratified to read them: more than half of them clearly mentioned God in their stories. How He gave them the faith and courage to go on, to persevere, to prevail.

A long time ago, centuries ago, it was written--and listen very closely--this describes us the mentally ill:

Blessed are the poor in spirit, for theirs is the kingdom of heaven. Blessed are those who mourn, for they shall be comforted.

Blessed are the meek, for they shall inherit the earth. Blessed

are those who hunger and thirst for righteousness, for they shall be satisfied. Blessed are the merciful, for they shall obtain mercy. Blessed are the pure in heart, for they shall see God. Blessed are the peacemakers, for they shall be called sons of God. Blessed are those who are persecuted for righteousness' sake, for theirs is the kingdom of heaven.

These, of course are the Beatitudes. They describe our experience. No where in this society of myths, stigma, prejudice, discrimination, and oppression against the mentally ill are there any more beautiful words that capture the beauty and dignity of those of us labelled mentally ill.

Personally, I haven't always kept my faith. I've strayed from the path many times. But I need God. I need religion. And I just want to mention some examples--good and bad--of how religion has fit into my life.

■I'll never forget the kindly priest who confided to me when I went to see him because of guilt over my depression, he confided to me that he had been in a hospital for religious who suffered from depression. And he shared that his director asked him to pray an hour a day. But this priest said he couldn't do it. The director said, "Can you pray half an hour?" and he said "No." "Twenty minutes?" "No." "Ten minutes?" "No." "Five minutes?" And the priest replied, "Yes, I think I can pray five minutes a day." That did a lot to dispel my guilt that I was finding it so hard to pray in the midst of a severe depression.

■I'll never forget being in the hospital dayroom and witnessing a minister come to visit an elderly lady who was depressed. A quite manic woman was dancing around the room at the time. This minister pointed to the manic woman as he sat down with his parishioner and announced, "There's a hopeless case!" My heart sunk. Because I knew the despair his parishioner was feeling herself. And sure enough, she answered him, "**I feel hopeless, too!**" Clergy

and friends, we need our hope. Each one of us, no matter how sick.

■I'll never forget the caring and sensitive man--and I want to name him by name, Reverend Ren Svanoë--who delivered the prayer at our 1992 Memorial Suicide Vigil. It was so compassionate, comforting, **and healing** for those of us who had lost someone through suicide and felt we hadn't loved or done enough and for those of us who have contemplated and attempted suicide.

■I'll never forget a hospitalization in Iowa City when I was in graduate school. Being in secularized institutions of higher learning for so long, where I think people can easily begin to see their own intelligence is so great that they deny even the existence of God, I had left the Church. But one particular day of intense agony, I did pray, in a way. I cried out, "**Oh, God, why am I suffering like this so much?**" But even as a non-Church goer, I heard God that day. I heard Him answer me: "**Because I love you so much.**" And I wept. I say this to remind everyone that we need to be reminded that God is our Creator and Father, our Savior and Safeguard--even when we claim not to know Him. We need to hear that.

■And I'll never be able to thank my good friend Jeanne Dalton-de la O, a Charismatic Christian, who tried for years to convert me from a nonbeliever to a Christian. And oh, was I resistant. But after one more failed relationship, and one more major depression, I turned to Jeanne in despair and lamented, "There'll never be a love, there'll never be a love strong enough for me to love myself." And she only smiled. And answered, "Yes, there's Jesus's love." And for the first time, for the first time, I thought, "Maybe she's right." I stopped putting her down as a Jesus freak and I turned to Him. And over the years of depression, Jeanne gave me an especially helpful Scripture verse to carry with me and give me solace and support. It is Jeremiah 29:11-14: **For I know well the plans I have in mind for you, says the Lord, plans for your welfare, not for woe! plans to give you a future full of hope. When you call me, when you go to pray to me, I will listen to you. When you look for me, you will find me. Yes, when you seek me with all your heart, you will find me with you, says the Lord, and I will change your lot.** We need to have that hope instilled and re-instilled.

■But I'll never forget how many good, well-meaning Christian friends have told me I don't need to see a psychiatrist, I don't need to see a therapist. "God is the Divine Physician, the only therapist you need." People need to accept that mental illness **IS** an illness, there are trained physicians and other mental health professionals--even some schooled in psychology and theology together--who are **NEEDED** to help the healing process. I've never heard a Christian tell a pregnant woman: "You don't need your obstetrician. God is the Divine Physician." Or a diabetic: "Quit seeing your physician, or quit taking your insulin." But I have heard Christians call psychotropic medications **"the work of the devil."** This is wrong, and potentially very harmful.

■I'll never forget the caring concern of my Charismatic prayer community. One night recently I was in a lot of emotional pain and when petition time came I asked humbly if the group would pray in tongues for me as I was in a lot of pain. To my extreme joy, they asked me to come up to the front of the circle and have prayer. They laid hands on me, they anointed me with holy oil, they prayed over me, they hugged me, they gave me a handkerchief to dry my tears. They were beautiful. And that is what I think Jesus meant to establish when he formed His Church--a body of believers who are there for each other.

■But I did regret, when they asked me where the pain was, that I said it was in my head. Because some there prayed to expel evil spirits. And that made me feel a bit--quite a bit--uncomfortable. **The mentally ill are not possessed by evil spirits.** But Dr. Coleman told me to think of it as the evil spirit of despair, and I think that diminishes the pain of it somewhat, but the misconception still persists among many very good and well-meaning religious. What I wished I had said to my Charismatic friends that night was "The pain is in my heart."

Because one thing I think you clergy and religious understand is this: mental and emotional suffering is of the soul, spirit, and heart--as well as of the body and mind. The world of psychiatry and medicine often see it as only medical. And we need a merging.

Please be open to us. Do not flinch from the hard task you are called upon to do. Remember us in your prayers. And as the late--and creative--advocate Inez Seibel was always so good at pushing: **LISTEN TO US. LISTEN TO OUR PAIN!**

You have the great gift of being blessed by the Holy Spirit, and so you can hear with ears that many others in society cannot. Continue to **PRAY WITH US FOR HEALING.** Jesus came so that we might have life and have it to the fullest. And by His stripes, we are healed. We are a people who need to have

hope for healing, for improvement, for change, for a better life, for a better lot, just as Jeremiah prophesied. Just as in our "PREVAIL Mental Health Consumer Bill of Rights," from which I will quote:

"We need to be accepted and welcomed, respected and valued as human beings. We deserve tolerance, love, and HOPE. We must learn that we can change, we can contribute, we can recover. WE HAVE A RIGHT TO RECOVERY; we have a right to the same quality of life as the rest of society."

Thank you for coming. Thank you for your great and important work.

--October 14, 1992

