

# THE DISABILITY RAG & Resource

March/April 1995

\$3.95

## Psychiatric Survivors:

Are We Part of the Disability Movement?

by Judi Chamberlin

**F**or more than twenty years, former mental patients have been organizing around the issues of patients' rights and self-help. We have grown from a few isolated, tiny groups to a national and international network, with conferences, newsletters, support groups, alternative self-help programs, arts organizations and numerous other activities. Yet we have usually considered ourselves separate from other disability activists, and the disability movement, in turn has often ignored or isolated us.

There are so many myths about people with psychiatric disabilities. We are thought to be violent, dangerous, out of

### Inside:

Medication  
Privatization  
DSM-4  
DIS-city  
The Abuse Excuse

Continued on page 4



# Psychiatric Survivors

*Continued from Page 1*

control, a threat to ourselves and others, unstable, incapable of defining or acting on our own best interests — and on and on. There are so many negative stereotypes, and very few positive images that we can model ourselves after. According to the media, we're either dangerous ax-murderers or pitiful homeless people. The stereotypes, of course, have little to do with the facts: most people with psychiatric disabilities are living successfully in the community, raising our families, working, going to school and, in general, leading essentially "normal" lives.

Many psychiatric survivors hide our disability, believing that if anyone knew the truth, we'd be stigmatized and discriminated against. Yet, at the same time, by refusing to identify ourselves as people with disabilities, we deny ourselves the support of other people like us, and the possibility of reasonable accommodations that could make our jobs, and our lives, easier.

I have always refused to hide in a closet. I have been public about my status as a former psychiatric patient — psychiatric survivor is the term I prefer — since I became involved in the ex-patients self-help advocacy movement more than twenty years ago. Nearly thirty years ago, I was diagnosed as a chronic schizophrenic. I was told what a limited life I could expect to lead. I originally entered a mental hospital voluntarily, seeking help for the overwhelming pain of depression which had followed a miscarriage. I expected to find help and understanding; instead, I found that

no one listened to me or took me seriously. Heavy doses of psychiatric drugs were the "treatment." When I protested that I didn't find them helpful, my opinions were simply dismissed. I soon found myself committed to a state hospital, where I remained for several months. It was the worst period of my life. My struggle to overcome the effects of this experience was what led me to become involved in the ex-patients' movement.

The overarching principles of our movement include:

- Self-determination
- Challenging (or questioning) commitment/involuntary treatment laws and practices.
- Challenging (or questioning) the medical model of mental illness
- Protection and expansion of legal rights
- Meeting people's needs through alternative non-psychiatric means, particularly client-run services
- Dealing with issues around stigma and discrimination.

Our movement is a civil rights movement. We are an oppressed group, oppressed by laws and public attitudes, relegated to legalized second class citizenship. The biggest legal barrier we face is the existence of involuntary commitment to institutions, and forced psychiatric treatment both in institutions and in the community. Until we eliminate this form of legalized discrimination, we are prevented from reaching full equality.

As we organized, we discovered that it was only with other former patients that we could express our anger, our

pain, our outrage, without being dismissed as "delusional" or "paranoid." In this respect, the psychiatric survivor movement has been fighting similar battles, and developing a similar philosophy, the overall disability movement. My work in the psychiatric survivor movement, and more recently as part of the larger disability movement, has convinced me that we must continue to advocate forcefully for ourselves and our right to live full and complete lives in the communities of our choice. There are still too many people who want to force us back into institutions, into subservience, back into seeking charity instead of taking our rightful place as full citizens.

We are all of us — no matter what our disability — under attack. While we have made some gains, the fact remains that people with disabilities are still largely unemployed or underemployed. We have few housing options. We are still discriminated against, still often seen as unable to manage our own lives without supervision. It's tempting to congratulate ourselves on how far we've come — we passed ADA and some other significant laws, no small accomplishment for a group without much money or influence — but we need to remember how far we still have to go.

Our cause is not served by divisions among ourselves, and yet those divisions go very deep. When those of us in the psychiatric survivor community look from the outside at the political accomplishments of people with physical disabilities, the groups look impressive and united. But as we begin to work more closely together — and I believe such unity is essential — it's clear that among the various groups

of people with physical disabilities there are major divisions and arguments.

Many years ago, when I first became involved with the ex-patients' movement (as it was then called), there appeared to be few, if any, points of unity with physically disabled people. Our struggle was framed as one about freeing ourselves from a label, "mental illness," that demeaned and disenfranchised us. After all, went the argument of the time, we're not disabled. Get rid of the labels, and the problems would disappear, or so we thought.

Of course, it's not that simple. As I have gotten to know disability activists, I have been struck over and over again by just how similar our problems are. It's not just people with psychiatric labels who have doctors controlling our lives and making our decisions. In a world that considers "normalcy" a prerequisite for people controlling their own lives and their own decisions, and which considers nearly any form of physical or emotional difference a medical problem, medical control of non-medical decisions is distressingly common. People with physical disabilities, like psychiatric survivors, often find themselves living in facilities and programs rather than in their own homes, not allowed to manage their own money or to make basic decisions about their lives.

The independent living movement and the psychiatric survivor self-help movement, although largely developed separately, have numerous features in common. Both are about being in control of our own lives, making our own decisions, seeking support from people who are like us

and share our perspectives. Both have shown that people with even the most severe disabilities can live in their own homes and make their own decisions, given the appropriate supports (often peer supports). And both face enormous opposition from "experts" who control the institutions in which great numbers of people continue to be incarcerated.

Why, then, have the two movements been so largely separate? A lot has to do with the fears and stereotypes each group has of the other. Until we start working together and learning from one another, we will not get to know one another, to get beyond our fears and our assumptions. I remember one of the first cross-

---

**If there was ever a  
time when we need  
to work together,  
now is that time.  
If we are divided,  
we will all lose.**

---

disability meetings I attended, a few years ago. I was scared that I would be misunderstood or disbelieved, and that my issues would be belittled or seen as different and separate. Instead, I found a welcoming atmosphere and a willingness to learn about psychiatric issues. Similarly I learned a great deal about the disabilities of the participants, which included mobility disabilities, blindness, deafness and mental retardation. I was fortunate that many of the activists there were national leaders who have become mentors and friends.

Another reason is that, because of separate funding streams and separate programs, we have often been denied the opportunity to get to know one another or to work together. Without personal knowledge of what people with other disabilities are like, we have tended to go our separate ways, often duplicating efforts and wasting our energies. In this atmosphere, misunderstandings and stereotypes are free to flourish.

The great triumph of the disability movement to date is the passage of the Americans with Disabilities Act. The ADA is a landmark piece of civil rights legislation that has the potential to assist people with all disabilities to participate fully in all aspects of life. The disability community worked for many years to bring this legislation into Congress and to secure its passage. For many reasons, psychiatric survivors were not fully involved in this effort. Nonetheless, during the final Congressional activity prior to passage in 1990, disability activists stood firm when attempts were made by congressional opponents to weaken the legislation by excluding people with psychiatric disabilities from coverage. Pat Wright, Justin Dart and other disability leaders took the principled stand that they would rather see the whole bill defeated than see the disability community divided.

However, many or most psychiatric survivors are unaware of the ADA or do not believe that it applies to them. There is a lot of education that needs to be done within this population so that people know about the law and can claim its protections. (Similarly, many people with physical disabilities are still unaware of the law or its ramifications.) Here

is an area where there is a clear need for the various disability groups to work together. Especially now, with the foes of ADA riding high in Congress and proposing amending the law or weakening enforcement, we need to stand together to defend our right to full citizenship.

We all know that the new Congress is no friend of people who are poor, disabled or otherwise disadvantaged. The recent election, however, may also serve the function of bringing the various disability groups more closely together, working in common and putting differences aside, than at any times since ADA's pas-

sage. In early January, about 80 people representing the various disability and advocacy groups gathered informally in Washington to discuss ways to respond to this challenge. In two days of meetings, one sponsored by the National Council on Disability, and the other by Justice for All, a new ad hoc group spearheaded and coordinated by Justin Dart and Becky Ogle, it was clear that all participants were eager to put aside whatever differences may divide us to respond to the current crisis. We were all charged with going back home to educate our new congresspeople about our

needs as disabled people, and to get our stories across to the public through the media. In the current political atmosphere of cost-cutting and contempt for anyone who is not rich and successful, the needs of people with disabilities are being portrayed as needless expenses rather than as investments in our lives and our futures.

If there was ever a time when we need to work together, now is that time. If we are divided, we will all lose. This year in Congress, at least two pieces of legislation important to disability groups are up for reauthorization: the Individuals with Disabilities Educa-

---

# Some Disabilities Are More Equal than Others

By Xenia Williams

**E**ast of the Mississippi and north of the Mason-Dixon Line is a small rural state I will call East Bumfuck. Recently my local paper, *Banana Belt Daily Blat*, ran a letter to the editor by a wheelchair user who was tired of people talking over her head to a helper pushing the chair. She explained, "I would like people to understand that we in wheelchairs are physically disabled, not mentally disabled, and that they can talk directly to us . . ." Wonderful of her. I thought, to point out who the real people are. Once

again, mental disabilities are a lower form of life. Cross-disability strikes again; and again I am reeling from the blow.

About a year ago, National Public Radio was showing how hip it has become about disabilities, and did a segment on its evening news program detailing the horror story of an elderly man who is deaf. Seems that when he was young and had a minor brush with the law, the cops could not communicate with him because he did not know sign language. (Also he was poor and African

American in a southern state; the cops were white.) They concluded he was insane, and he was put in the state mental hospital, where he spent the next 50 years.

Over and over the reporter stressed what a tragic thing this was, because *the man was not mentally ill; he was deaf*. The message came through clearly that, if he had actually been mentally ill, IT WOULD HAVE BEEN PERFECTLY OK for him to be locked up in a snake pit for 50 years. Thank you, NPR, for being so enlightened.

tion Act (IDEA) and the Protection and Advocacy for Individuals with Mental Illness (PAIMI) law. We may well see attempts to "amend" (that is, to gut) ADA. There will in all probability be an attempt to place many of the programs that people with disabilities depend on into block grants to the states so that governors will have discretionary control over which programs to fund. If that happens many disability-specific programs may well disappear and the level of services from state to state will vary drastically. Further, income support programs are under attack. If all these efforts succeed, people

with disabilities will suffer; indeed, many of us may die.

There will be attempts to divide us into various disabilities and to set us against one another. Part of the argument against the reauthorization of IDEA, for example, is that it allows children with psychiatric disabilities to remain in classrooms even when they commit violent acts. In fact, there are provisions in the law for such emergencies, but if we allow this effort to separate out a category of disability as unworthy of legal protection, we will all be the losers.

There are needs for coalition beyond disability, to en-

compass all poor and disadvantaged people who are under attack. But first we must ensure that disability groups and advocates are working together, aware of one another's issues and determined to fight any attack on any of our rights. Psychiatric survivors, people with mobility disabilities, blind people, deaf people, those with learning disabilities, those with head injuries — *all* of us are under attack! *All* of us must work together! The time is now! □

*Judi Chamberlin is an Associate at the National Empowerment Center in Lawrence, MA.*

More recently, National Public Radio again displayed their concern for people with disabilities with an interview of a poet who uses an iron lung. One poem tells of a mean nursing home employee who is described as a "crazy bitch." Wonderful that this is the nastiest thing he can say about her. (Remember the Iraq war, when each culture revealed what they considered the ultimate insult? The Iraqis referred to George Bush as "Satan." The U.S. media's favorite word to describe Saddam Hussein was "madman," although there was no indication that the Iraqi leader had any disability, and appears to be just another power-hungry politician ready to spend lives like water).

### *No Pity and No Clue*

When a person I respect highly on the national scene plugged the book *No Pity* as an excellent take on the disability rights movement, I picked up a copy. I was horrified. Yes,

[author Joseph P.] Shapiro gives a good account of the Gallaudet strike, the genesis of the Independent Living Centers, the ADA, etc. And he even does an excellent job of dispelling myths about cognitive disabilities ("mental retardation") and people so designated. One of his methods of educating readers about whatever disability is to introduce them to individual people, naming them and talking about their lives, contributions and abilities.

We lunatics struck out completely. At first I thought Shapiro was just going to ignore us, aside from the occasional mention in lists of disabilities. No such luck. Instead of just barely acknowledging our existence in the disability world and downplaying the significant numbers of psychiatrically labeled people in hopes that our bad odor will not rub off on the respectable disabilities (as is often done by other disabilities and nondisabled advocates), he actively rein-

forces bad stereotypes about crazy people.

The *ONLY* person Shapiro describes as having "had a history of mental health problems" is a nameless personal care assistant to a wheelchair user. This assistant abused the wheelchair user in a number of ways, such as tying him to his bed in response to delusions. Since this is the only person described in *any* detail with a psychiatric disability, the message about us from Shapiro is very clear. Don't hire these people; stay away from them; they are dangerous; they will hurt you. Much as if the only person labeled "mentally retarded" in his book was an individual who set houses on fire just to watch the glow.

Various more subtle slams at the lunatics permeate *No Pity*. A group representing people who stutter are described as fighting stereotypes: "... its members are hurt by widespread assumptions that people stutter because of shyness or some emo-

tional disorder when in fact they are no different psychologically from anyone else." Shapiro certainly registers no hint of disagreeing with the notion that being different psychologically is highly undesirable, and that other disabilities are correct to distance themselves from us.

The latest issue of *Mouth* pushes the newly released paperback edition of *No Pity* as "smart, objective, and a real scoop. Highly recommended." The newsletter of the East Bumfuck Center for Independent Living plugged *No Pity* and advertised it as available in its lending library. After I complained to the editor that there should be at least a "Surgeon General's Warning" issued to let people know the book is poison on psych. disabilities, her response was to plug the book again in the following issue, with no caveat, in a format accessible to people who are blind. In the many disability publications I have seen praising *No Pity*, not a single one has breathed a whisper about how it trashes the crazies.

People with psychiatric and cognitive disabilities too often appear in cross-disability publications in other than the first person, even while such journals make a huge point of how people with disabilities know ourselves best and can speak for ourselves. (Some confusion, perhaps, that we are *veterinary patients*, not *mental patients*.) Providers frequently appear as the authorities on us.

People with cognitive disabilities do even worse on this: I don't recall ever seeing an article authored by (or even "as told to") a person designated as "mentally retarded" in a cross-disability publication. (The Oregon Developmental Disabilities Council is now

testing a pilot edition of a manual on inclusive boards, etc., called "Not Another Board Meeting!" which contains a great article by Gayle Gardner, a person with a cognitive disability. She is the current board president of the Oregon protection and advocacy system.)

Some of these non-labeled people also have a weird idea of what we need. A recent article on how prison inmates with disabilities suffer pushed increasing utilization of the Not Guilty by Reason of Insanity (NGRI) and other mental incapacity special deals as what the MI/MR crowd needs. What we actually need is to do away completely with NGRI, since it is the foundation on which the involuntary psychiatric and involuntary mental retardation systems are built. A state lawyer here in East Bumfuck, whom I usually see across courtrooms where he is trying to lock my friends up in the loony bin, agrees with me about this. (If you can't hold people accountable for their actions in the standard way, then you have to do something else with them. The involuntary "treatment" system, which punishes us for what we think and for someone's fuzzy predictions of what we might do in the future, *RATHER THAN WHAT WE ACTUALLY DO* like other adult citizens, is the "something else.") What we need is equal civil rights, not special arrangements that imply that those with mental difference, or alleged to have same, do not qualify as people but are really wild beasts needing to be restrained. Sure, this may mean that the handful of people who escape execution by NGRI will die, but what about the many many more who die in restraints and seclusion rooms, or of iatro-

genically induced drug effects

By far the most dangerous (and most believed by other disabilities and nondisabled people) of those who claim to speak for the "mentally ill" is a group of organized relatives of persons who use, have used, or have been used by the mental health system. I will call them the Control-Freak Parents from Hell (CFPH). CFPH is (mostly) comprised of parents of labeled people who have sought refuge in a cult-like belief in No-Fault Brain Disease, which conveniently lets off the hook any of them who may entertain guilt for possibly screwing up their kids. It allows them an excuse to keep on running their kids' lives while whining about what a burden it is. They take authority not only from their fake science (none of which holds up under any kind of objective examination), but from the eternally patronizing provider principle that "since you are forced to accept help from us because all the other choices seem worse, we have a right to tell you what to do. Be grateful." Sound familiar?

Control Freak Parents from Hell (at least those in power: dissent in the ranks is not tolerated) love forced "psychiatric treatment" and push lock-em-up and drug-em-up laws in every state. They want their relatives to be quiet, take their meds and stay sick forever. This will then validate the correctness of their belief that we are genetically defective and cannot be cured of our "neurobiological brain disorder." (Funny how a person who gets convinced that she/he will be a mess forever is very likely to fulfill that prophesy!) Psychiatrists and pharmaceutical companies (who, not coincidentally, give large amounts of money to Control Freak Parents from Hell) love

CFPH for obvious reasons. CFPH, predictably has some Clarence Thomas-like "consumers" in their sway, who understandably enjoy the approval that accompanies their willingness to be displayed championing shock, biopsychiatry, etc.

Unfortunately, cross-disability groups made up largely of disabilities who have more basic civil rights (e.g., to be left alone, refuse offered "treatment," not be locked up specifically for one's disability) than do mental disabilities, and concentrate mostly on securing disability-related services, are too often welcoming to Control Freak Parents from Hell, since they, too, pursue services (even against the will of their relatives). The fact that CFPH pushes Forced Treatment too often does not bother them.

Forced Treatment *DOES* bother *ME*. Involuntary psychiatric hospitalization is kidnapping. Forced drugging is rape. It is an abomination and a basic violation of the right to be left alone. I have personally been force drugged: held down by three people and injected with massive doses of a chemical straightjacket that paralyzed my ability to think. Cement in the brain. Any organization that pushes gang-rape mind-fuck does not belong in a rights coalition.

## The "rehabilitation" Of Vincent Van Gogh

An article last summer in a familiar journal\* tried to set the record straight about the artist: "... Vincent Van Gogh, who is now thought to have had epilepsy rather than deserving to be locked up ..." It's nice that the author, who has a physical disability, is letting

\*The Rag *pleads guilty*.

readers know that Van Gogh was really OK and not a dirty smelly mental patient who was therefore dangerous and deserved to be locked up because of his disability. Leave no doubt that mental illness equals violence, or that a psychiatric disability equals bad, while attributing the artist's differences to a physical disability cleans up his reputation.

Another familiar journal described the difficulty of getting FBI action on a person's illegal confinement to a rehab facility. Psychiatrically labeled people don't bother to call the legal authorities when we are kidnapped and held against our will. With us, it is legal in all fifty states. Funny how some of the worst abuses against people with other disabilities occur when they are told that they are "unstable" or "acting out" or any of the mental health phrases. (You have just lost your personhood.)

You people need to realize that as long as lunatics don't have civil rights, ANYBODY can be put in our category and lose theirs. Psychiatric labels are very easy to come by (I have an impressive collection). The psychobiz is a huge, fast-growing and extremely profitable industry. If you don't stand beside the crazies, there may be no one left to come to your aid when *YOU* are labeled and hauled away by the Thought Police. □

*Xenia Williams, after spending a geologic age in the mental health system, now only consumes "fuzz therapy" from her Siamese cats Paris and Cassandra. Her favorite buttons read: 1) Places to go, people to annoy; 2) I used to be sane but I got better; and 3) I don't need therapy — I need money.*

## ADAPT, Baltimore, May 14-18. Be there!

As *The Rag* went to press, the Senate had approved legislation opposing so-called unfunded mandates, and House discussion was moving forward. The Clinton Administration and the National Governor's Association had come to some agreements about moving more aspects of welfare administration from the federal government to the states.

Some governors are already starting to slash into existing Medicaid programs, endangering existing attendant or assistance services. In New York, the biggest cut proposed by Gov. George Pataki's Medicaid Transition Task Force would be to home care services for the disabled and elderly. (The second biggest cut would be from health care rationing.)

The day after the Senate passage, an op ed piece in the New York Times quoted several recipients of housekeeping services. One, 70-year-old man who uses a chair because of a spinal condition, put it acutely and concisely: "Why turn a situation that can be remedied, or at least controlled, into a life-threatening one? Housekeeping services allow people to be viable and productive. Compare the governmental and societal costs of having an individual stay even two days in the hospital versus the small cost of housekeeping a couple days each week."

Join ADAPT's ongoing campaign to keep people out of nursing homes and able to live in our communities. The opposition is getting more and more monolithic and organized. The voices of the disabled and elderly must get louder and stronger. For more information about ADAPT's action in Baltimore May 13-18, call their national headquarters at 303/733-9324 or contact your local coordinator.