

By Judi Chamberlin

Citizenship rights & psychiatric disability

The following is a speech given by Judi Chamberlin at the World Mental Health Day Conference in Stockholm, Sweden, on October 10, 1996.

On the occasion of World Mental Health Day, I would like to talk to you about rights and rights' protection for people labeled "mentally ill". All too often, this subject is approached as "the rights of the mentally ill", as if being "mentally ill", or carrying that label, means that this group has special, or different rights than other people. Documents concerning the "rights" of "the mentally ill" usually begin (and often end) with "treatment rights": the "right" to treatment that is decent, respectful, adequate, and so forth. I submit to you that this is the wrong way to think about rights.

By rights, I mean those fundamental expectations that govern the relationship between individuals and societies. In modern, western societies, rights of individuals are conceptualized as protections against arbitrary so that individuals retain personal choice and decision-making.

Autonomy is a key underlying value; the adult individual is free to make choices that differ from social norms or expectations, so long as those choices do not bring the individual into conflict with established civil or criminal law. Rights can only be abridged, in theory, when individuals come into conflict with society according to established laws, and then only after certain procedural safeguards have been met.

These practices evolved over long periods of time, and mark an advancement in social relations from absolute rule by a monarch or by the state (which, of course, still continue in many parts of the world). The right of the individual to be free from arbitrary exercise of state power is perhaps the key difference between the democratic nations of the world and those that operate under other systems. Their cross-cultural

value is recognized by documents such as the Universal Declaration of Human Rights, which hold that all adults, anywhere in the world, should be free to make basic life choices for themselves.

Why, then, does the supposedly medical diagnosis of "mental illness" carry with it such a profound effect on the rights of those so labeled? People with psychiatric labels can, in almost every country of the world, regardless of its political and social system, be deprived of their liberty and put into mental institutions against their will, often indefinitely. They can be required to take psychiatric drugs, be given electroshock treatments, even be lobotomized. They can lose their civil rights, such as the right to marry, the right to enter into contracts, the ability to work in their chosen professions, and the right to custody of their children. Often, they are socially ostracized, and such stigma may extend to their relatives. Such things don't happen only in so-called "backward" countries. Last year in the U.S.A., for example, it was revealed that leading medical organ transplant centers maintained "blacklists" of people deemed "not suitable for transplantation"; these lists included people who had been diagnosed with mental illness, and people with mental illness in their family history.

Involuntary commitment, forced treatment, and psychiatric control over decision-making are really not complicated issues, despite the efforts to make them seem so. The fundamental question is this: why do we take one group of people, those labeled "mentally ill", and deny them basic rights? We hear talk about "special needs," "vulnerabilities," "at-risk populations," and lots of other terms designed to obscure this fundamental question: it is ethically justifiable to confine people against their will, to subject them to procedures against their will, or to overrule their life choices on the basis of an ostensibly medical diagnosis? I believe that until we frame this question

properly, as a human rights question, we will continue to make the simple complicated. I believe that my views about choice and voluntaries are applicable to all people deemed incompetent by psychiatrists. Further, I think that any person, regardless of label (or unlabeled) who can express his or her own wishes and desires, no matter how irrational they may appear to others, deserves to have those wishes respected. People who are genuinely incapable of such expression probably fall beyond the scope of my argument. By genuinely incapable, I mean people who are comatose or otherwise unable to communicate not those who are clearly communicating what others may not want to hear.

Supposedly, we live under the rule of law. Just because we believe that someone is likely to commit a crime, we cannot put that person in jail. The reasons why we believe that someone is a likely criminal often have to do with that person's membership in a class. Nearly every society has its minority groups, whether they are racial, ethnic, or otherwise defined, that are often believed by the dominant culture to be dangerous and deviant. It's all right to abridge their rights, in this way of thinking, since left to their own devices, they will undoubtedly commit crimes or otherwise upset the social order. I believe this is a basic injustice.

Let us look at the mental health system in the same way. We are told that certain individuals are vulnerable to "mental illness." We are also told that psychiatric interventions are what they "need". Is it justifiable, therefore, to ignore their expressed wishes and proceed on the basis of the supposedly superior wisdom of those who have the power to make the definitions, and enforce the consequences? I believe that this, too, is a basic injustice.

According to psychiatrists, most people at some point show some "symptoms" of "mental illness," and large

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numbers of people are seriously "ill," yet most of them manage quite well without psychiatric interventions. Most psychiatrists seem to think that a little psychiatry would be good for everyone, and that not knowing that you are "ill" is one of the "symptoms" of the "illness," and so people need to be coerced. But this is not the way things are supposed to work in a free society.

The ethical system (if I can call it that) that drives the involuntary treatment system is paternalism, the idea that one group (the one in power, not oddly) knows what is best for another group (which lacks power). The history of civilization, in part, the struggle against paternalism and for self-determination. People in power are always saying that they know what is best for those they rule over, even if those poor unfortunate individuals think they know best what they want. The powerful seldom cast their own motives in anything but benevolent terms. Rulers and slave masters like to think (or pretend) that their subjects love them and are grateful to them, often having to ignore much evidence to the contrary. The struggle for freedom has always been seen by the powerful as a denial of the obvious truth of the superiority of the rulers.

All of us should be free to follow our own dreams. The U.S. Declaration of Independence states that basic rights include "life, liberty, and the pursuit of happiness." As we each pursue happiness, most of us seek economic stability, good and comfortable places to live, choices of daily activities, and satisfying

companions for friendship and love. As the irrational, fallible human beings we are, our lives are an endless series of steps and missteps in pursuit of those dreams. Those who would overrule, on the basis of "incompetence," the dreams of others, are usually concerned with safety issues, with little regard to happiness. If we are truly concerned with protecting people we may deem to be incompetent, surely we must zealously protect their right to pursue happiness as well as their right to be safe. Otherwise, we are prescribing one standard for so-called normals, which allows (and even celebrates) the primacy of the pursuit of happiness, and another, more sober and more severe standard for those whom we presume to decide their "best interest."

This historic confusion of medicine and power skews our language and our thinking. We hear arguments for the "medical model" that so-called "mental illness" is an illness like any other. If psychiatrists

toward so-called "incompetents," to protect them from their own shortcomings. But I believe that competence, like beauty, lies very much in the eye of the beholder. Take, for example, teenagers who choose to smoke cigarettes. Almost by definition, teenagers are unable to judge long-term consequences, or to see themselves as old, and so many discount anti-smoking education that focuses on the development of the disease twenty or thirty years down the line. Are these teenagers incompetent, or are they simply showing some very human traits, putting current gratification above future considerations? I believe that most so-called incompetent decision-making is this same process at work, viewed through the lens, however, of a person's label.

Adults, too, often act against their own best interests, with the full legal right to do so (providing they have not been labeled "mentally ill"). Overeating, not

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want to be like other doctors. I believe they should do as other doctors: wait for patients to come to them, and treat those patients as free agents. No one "chooses" to get cancer or heart disease, or diabetes. But a person with one of these illnesses remains a free moral agent, who can choose to seek medical treatment, to enter a hospital, to undergo surgery or other medical procedures, or, equally important, can choose not to do so. The fact that a person has cancer (a real illness) does not give us, as a society, the right to lock that person up and treat him or her if that person's choice is to go to a faith-healer, or to ignore the situation.

Supposedly, the difference is "competence". We allow people we deem competent to make irrational or wrong decisions, while assuming a paternalistic stance

exercising, taking up dangerous hobbies (such as skydiving), driving too fast, and getting drunk are all common behaviors that are certainly not in the best interests of the individual, or of society as a whole. Yet we respect people's individual choices to engage in these activities, as I believe we should. If you are considered normal, you have the right to be wrong.

Therefore, whether or not there is or is not an underlying genetic or biochemical cause of "mental illness" is irrelevant. Despite all the research and all the theorizing, the schizophrenia gene or the schizophrenia germ has never been demonstrated. I believe that it never will; we can no more find the "cause" of complex human behavior in brain chemistry than

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we can find the "cause" of poetry. But even if there were real, biological diseases, psychiatrists wouldn't therefore derive the power to lock people up and treat them against their will, or to overrule their personal life decisions. These are legal, and ultimately moral decisions, not medical ones.

What, then, is the best way to help people who are confused, who are behaving in non-ordinary ways, who seem to be

then can people approach one another as equals, face difficulties, and search for solutions.

Defining a person's difficulties as psychiatric is a rejection of the reality of people's experiences. Psychiatric diagnosis is, in part, a process of decontextualization, of denying the real meaning that supposedly dysfunctional behavior has to the individual. A person may behave in ways that other people can't understand, but ways which have meaning and value for that person in the contest of their lives. Turning behavior, thoughts, and feelings into "symptoms" actually gets in the way of understanding and helping. What is really helpful is contextualization, helping the

seem quite willing to sacrifice our freedom in the name of benevolent paternalism.

The struggles against slavery against the subjugation of women, and against racial and ethnic discrimination are, ultimately, moral issues. Psychiatric survivors, also, are fighting for our rights. We cannot wait for the lawyers and judges to decide when or if we are "ready" for freedom. Wanting to be free is not a delusion.

In many countries of the world, people who have experienced psychiatric treatment are speaking out about these issues. Our organizations represent people who are refusing to remain voiceless and powerless. We are no longer willing to let others speak for us, whether those others are psychiatrists, lawyers, relatives, or politicians. We are citizens of our countries and we want to be treated as equal to other citizens. We have joined together because we recognize our own humanity when others have denied it. We have found support and friendship from others who have shared our experiences. Often, we have been lone voices speaking out about problems other people don't want to think about. It's easy for others to assume that the issues of mental illness and its treatment are being dealt with by experts. But the experts have not experienced our pain and our determination to change the conditions we have experienced. Our expertise comes from our lives.

In my years of activism in the patients' movement, I've seen many changes. Not too many years ago, former patients were not invited to speak at conferences like these. Today, our participation is welcomed, our opinions are solicited, our voices being heard. But the continued existence of involuntary commitment, of prison-like mental institutions, of discrimination and segregation, show how far we still have to go to reach our goals: full citizenship, equality, and human dignity. □

"We allow people we deem competent to make irrational or wrong decisions, while assuming a paternalistic stance toward so-called "incompetents," to protect them from their own shortcomings. But I believe that competence, like beauty, lies very much in the eye of the beholder."

out of contact with the ordinary world and society's expectations? This is another point where discussion usually gets muddled; opponents of involuntary psychiatric interventions are supposed to propose "alternatives," as if a better way to deal with these problems was the solution to the problem. It's like asking what the alternative is to slavery. Are opponents of slavery supposed to suggest "better" ways of "dealing with" a troublesome population? The ethical position toward slavery is to see it as a moral wrong, and freedom not as a "treatment" or an "alternative," but as a moral imperative. Similarly, the "alternative" to psychiatric domination is also freedom. Freedom does not mean that the problems of the former slave, or the former patient, disappear, but it does mean that the power over the individual that was formerly held by the slave master or the psychiatrist does disappear. Only

person to understand that thoughts, feelings, and emotions, do have meaning within the context of that person's own life and experiences. Unlike involuntary psychiatric treatment, this kind of real, individualized help is impossible without the active participation of the individual being helped.

However, I am not going to talk today at any length about the self-help alternatives that have been developed by the psychiatric survivor movement as a way of helping people to deal with the pain that is often a significant part of life. That is another topic for another time. It is not the job of the psychiatric survivor movement to solve social problems that have led to the present unjust system. Instead, it is our job to serve as the moral focus of this debate, to represent the powerless in our struggle for fundamental justice. It is clear that we cannot leave our fate in the hands of lawyers, judges, and psychiatrists, who