Section 4

Users' views on coercive treatment

Coercive Treatment in Psychiatry: Clinical, Legal and Ethical Aspects, First Edition.
Edited by Thomas W. Kallert, Juan E. Mezzich and John Monahan.
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12 The moral imperative for dialogue with organizations of survivors of coerced psychiatric human rights violations

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12.1 Overview – coerced psychiatric procedures lead to an insurmountable power imbalance

I personally experienced coerced psychiatric procedures in a variety of ways over a three-year period as a young adult. Because of what I perceived as my unjust and harmful mental health care, I felt passionately motivated to become a community organizer in the field of human rights in mental health. In my opinion, the coerced psychiatric procedures I was subjected to were significant violations of my human rights that profoundly traumatize me to this day.

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As a grassroots activist in the field of mental health advocacy for the past 35 years, I have heard moving stories from hundreds of other individuals who identify themselves as survivors of coerced psychiatric human rights violations, often far more traumatic than mine. I feel privileged, humbled and thankful to call many of these psychiatric survivors my lifetime friends and colleagues. Because of my unique career, I have had a front seat watching the beautiful resilience of the human spirit overcome not only their original mental and emotional crises, but also the insidiously complex trauma that occurs when one feels betrayed by those who are charged and licensed by our society to provide care, healing and protection.

Too often, individuals, who for the first time hear about our little-known social change movement led by survivors of psychiatric abuse, claim that the kinds of violations that I and other leaders suffered decades ago were remnants of a dark age and no longer occur. As the director for the past 25 years of an international non-governmental organization (NGO) that works for the human rights of people in the mental health system, MindFreedom International, I can testify that nearly every day our office receives new, moving, poignant, personal reports of abuse in the contemporary psychiatric care system, usually related to some type of coercion. The types of abuse I hear about have continued unabated throughout all these years, to the present time. My subjective perception is that this psychiatric coercion is increasing, and in fact appears to be expanding rapidly into poor and developing countries.

I discuss coercion in psychiatric care here neither as an academic with an advanced degree, nor as a licensed mental health professional with clinical experience, because I am neither. Instead, I question coercion in the mental health field as a psychiatric survivor activist who has devoted his adult life to promoting human rights as the very foundation of mental and emotional well being. I will briefly review what I have learned from my vocation, and discuss what I categorize as three general types of psychiatric coercion:

1. **Force: physically imposed mental health care over the expressed wishes of the subject**

   For example, some individuals diagnosed with psychiatric disorders are now under court order to take prescribed psychiatric pharmaceuticals over and against their expressed wishes, even though they are living peacefully and legally outside of an institution, in a community setting in their own home. In many instances, if such an individual refuses to take a prescribed psychiatric drug, then he or she can be immediately institutionalized. Known by a variety of terms such as ‘involuntary outpatient commitment’ or ‘compulsory community treatment’, this approach is an example of the expansion of coerced psychiatric treatment from the back wards of locked psychiatric institutions, to the front porch of our own homes in our own neighbourhoods. This spread of what often amounts to coerced psychiatric drugging in our communities has become widespread in North America, Europe and Australasia [1].

2. **Fraud: misinformation by licensed mental health professionals in order to alter the behaviour of mental health clients**
   For example, as we will see, back in the 1970s I was told by my psychiatrist that I would absolutely need to take prescribed psychiatric pharmaceuticals for the rest of my life because, he alleged, I had a scientifically proven, genetically caused, chemical imbalance. While I respect others who make the personal health care decision to take prescribed psychiatric medications, apparently my psychiatrist was misinformed. I have been off of all psychiatric medications since 1977.
3. **Fear: the terrifying belief by an individual seeking mental health care that he or she has no alternative available, other than a very narrow range of choices, typically limited to a conventional medical model**
   For example, many individuals, contacting our office to complain about their mental health care, report that they are not offered psychotherapy or other non-drug psychosocial approaches at all; instead, they are often prescribed a perplexing and frequently changing combination of many psychiatric medications. A wide array of non-drug alternatives is being utilized by other individuals who are diagnosed with severe mental and emotional problems to reach recovery, but these options are often not readily offered or available to the general public. One of the more promising fields is the use of peer support to augment or replace other types of psychiatric care [2].

In order to explore the psychosocial and ethical impact of these three forms of psychiatric coercion, I believe that open, mediated dialogue between mental health professional organizations and organizations representing those who have experienced psychiatric human rights violations is a moral imperative. I argue that a number of psychiatric survivor organizations have attempted such dialogue, but so far these invitations have not been enthusiastically reciprocated. While we must never give up, I conclude that we must learn from other successful social change movements in history who have represented extremely marginalized and disempowered populations, such as the US civil rights movement led by African Americans. We must consider the necessity of moving into an era of international nonviolent direct action, including peaceful cultural and civil disobedience protests.

12.2 On the sharp end of the needle – my recruitment to human rights activism

My personal introduction, to what I feel can be an astounding power imbalance between psychiatrist and client, arrived when I was a college student experiencing overwhelming mental and emotional problems. I had grown up in a working class neighbourhood on the south side of Chicago in a household with loving parents, and I won several scholarships to attend Harvard. Unfortunately, five times during my sophomore, junior and senior years I entered into severe mental and emotional crises, and ended up inside of psychiatric institutions. During my stays on these psychiatric units, I would often feel pressured by staff to take powerful psychiatric pills, and I often tried to refuse. More than once, staff brought me to an empty solitary confinement room, held me down on a bare mattress, pulled down my pants, injected me in my buttocks, and then left me there alone for a few hours to a few days.

The subjective experience of being forcibly injected with psychotropic drugs and left isolated has created one of my longest-standing recurring nightmares. There I was, a confused and frightened young person. I felt at the time that I needed respite, advice, support and comfort. Instead, the impact of the coerced psychiatric drug felt like a wrecking ball to the cathedral of my mind, a mind which was indeed troubled, but which I valued nonetheless. While on coerced neuroleptic psychiatric medication, also known as antipsychotics, the more I tried to focus and think, the more difficult I found the task. I developed a number of physical side effects to the medications that some might consider trivial, but that I found upsetting, such as muscle contortions in my neck and blurry vision. All in all, I felt humiliated, disrespected and defiant. I certainly did not feel a high level of trust with my mental health providers that might have been more conducive to a therapeutic relationship.

I was exposed to a variety of coercive acts while in psychiatric institutions. For instance, upon admission my basic rights were immediately taken a way, and then slowly given back as privileges for behaviour that was considered appropriate. My every movement was monitored and controlled. Any seemingly peaceful rebellion by me – such as questioning staff – could be misinterpreted as violent, and result in another forced drugging. For example, once, when I complained to staff about something on the ward, a staff member condescendingly gave me a cookie in a paternalistic gesture. I took the cookie and crumbled it in my hand. Immediately guards were summoned for another forced drug injection, even though I quickly and compliantly dropped every crumb of the cookie into the garbage can. My frantic gesture of cleanliness was futile, because the machinery of another forced psychiatric drugging had already been triggered.

The impact of these experiences alienated me far more from our society than anything I had experienced before or after. I remember with special clarity one particular moment when I was standing in my solitary confinement room after another forced psychiatric drug injection. I was looking out of the cell window, which was covered by an impenetrable steel mesh. I symbolically pounded the mesh a few times with my fist, slowly and methodically, doing no damage to either the mesh or my fist. But I vowed that when I got out I would seek to change how the mental health system treated people. I now refer to that solitary confinement room on the ground floor of Bowditch Hall at McLean Hospital in Belmont, Massachusetts, as my recruitment room to become a community organizer of mental health consumers and psychiatric survivors.

In my senior year, I am grateful that Harvard's social service agency, Phillips Brooks House (PBH), placed me as an intern in one of the early psychiatric survivor activist organizations in Cambridge, Massachusetts. Inspired by the ferment of the times, these groups began springing up in the USA, Europe and Canada in the early 1970s. The moment I entered the little store front where this group of psychiatric survivors met, I discovered I was not alone. Finding courage through mutual support, we exchanged our personal stories, and learned that others were seeking to significantly change the mental health system. This is where I met Judi Chamberlin, who was preparing to publish what would become an influential book, *On Our Own*, which proposed to transform the mental health system by creating peer-run alternatives [3]. Judi would become an internationally influential advocate for mental health consumers and psychiatric survivors. She was later to write about what brought her into this work:

> Being a patient was the most devastating experience of my life. At a time when I was already fragile and vulnerable, being labeled and treated only confirmed to me I was worthless. It was clear my thoughts, feelings, and opinions counted for little. I was presumed not to be able to take care of myself or to make decisions in my own best interest, and to need mental health professionals running my life for me. For this total disregard of my wishes and feelings, I was expected to be appreciative and grateful. In fact, anything less was taken as a further symptom of my illness, as one more indication I truly needed more of the same. [4]

The fifth and final time I was institutionalized, I was able to contact this grassroots group and ask for advocacy and moral support. Thankfully, my family, which had at first been compliant with suggestions by mental health professionals, had become more sceptical. As recounted in the book, *A Way Out of Madness: Dealing with Your Family After You've Been Diagnosed with a Psychiatric Disorder* [5], my family began to question the wisdom of the aggressive mental health care I was experiencing. Even today, I find the fact that my family took steps to protect my human rights decades ago as personally healing. As I prepared to assert my rights and leave my last psychiatric institutionalization, the mental health authorities apparently contacted my family to enquire about the possibility of seeking a court order to prevent me from leaving McLean Hospital. My mother famously replied on behalf of my family, 'If our David wants to try freedom we support him.'

After this final institutionalization, I wrote my senior paper at Harvard about my experience of volunteering with Judi and others. I explored how people, who have been hurt in such a deep way, appeared to feel compelled to innovate unique, empowering styles of organizing their group, in an attempt to prevent authoritarianism which might retraumatize them. Somehow, despite all of my problems and institutionalizations, I managed to graduate with honours from Harvard in 1977.

During the decades since I have noted that the scientific literature in psychiatry frequently hypothesizes about a possible chemical imbalance as being at the root of many serious mental and emotional problems. As we will see, strong scientific evidence for such a chemical imbalance apparently remains illusive to research scientists. However, as a community organizer I can offer my personal observation that a vast power imbalance exists between the psychiatric profession and their customers. When there is such a disparity in power, I have often found a silencing effect that can mute or distort the voice of the individual who finds him- or herself so shunned and discounted.

The enormity of the emotional harm caused by coercion in mental health care can be emotionally devastating, and even physically deadly. In an attempt to maintain the memory of those whose lives have been shortened due to mental health abuse, many of us call ourselves, as I do, 'psychiatric survivors'. I have listened to stories of individuals who have received the overt brutality of repeated electroshock (also known as electroconvulsive therapy or ECT), against their passionately expressed wishes. I have heard stories of being held in restraints for hours, or even days. I have several friends who personally experienced the now-abandoned insulin coma therapy, describing the pain of the forced experience as torture [6]. It is impossible to rank all the types of psychiatric coercion by the harm that is caused. A common denominator is that psychiatric survivors say that the unjust deprivation of liberty itself is always harmful.

One of the leaders I met when I first became active as a community organizer was Ted Chabasinski, a well-respected leader in the social change movement led by psychiatric survivors, who would later become an attorney working as a mental health advocate. As a child in the 1940s, Ted was subjected to well-documented and unfathomable abuse in a programme in New York State that was experimenting with the administration of ECT on children as young as three [7]. Ted was only six years old when he received his own experimental involuntary electroshock [8].

Ted recalled the memories in an interview he provided to MindFreedom International. He remembered thinking as a child, 'I won't go to the shock treatment, I won't!' Ted said it took three attendants to hold him:

> I wanted to die but I really didn't know what death was. I knew that it was something terrible. Maybe I'll be so tired after the next shock treatment I won't get up, I won't ever get up, and I'll be dead. But I always got up. Something in me beyond my wishes made me put myself together again.

Even as such a young, frightened child, Ted tried to find ways to somehow maintain his identity. Said Ted,

> I memorized my name, I taught myself to say my name. 'Teddy, Teddy, I'm Teddy... I'm here, I'm here, in this room, in this hospital. And my mommy's gone...' I would cry and realize how dizzy I was. The world was spinning around, and coming back to it hurt too much. I want to go down, I want to go where the shock treatment is sending me, I want to stop fighting and die... and something made me live, and to go on living I had to remember never to let anyone near me again.

Ted recounts that he spent his seventh, eighth and ninth birthdays locked in solitary confinement at Rockland State Hospital.

> I had learned the best way to endure this was to sleep as much as possible, and sleeping was all I could do anyway... Sometimes there was nothing in the room, nothing at all, and I would lie on the mattress and cry. I would try to fall asleep, but I couldn't sleep 24 hours a day, and I couldn't stand the dreams. I would curl into a ball, clutching my knees, and rock back and forth on the mattress, trying to comfort myself. And I cried and cried, hoping someone would come. 'I'll be good,' I said.

Psychiatric survivor Janet Foner, one of the founders of the support coalition united through MindFreedom International, listed some of the more distressing aspects of her institutionalization:

> The worst parts of being in an institution were: Being locked in seclusion twice. Being on drugs and not being able to stay awake, be aware, or move much. Gaining 30 pounds. Being made to stay there in confinement so long. Boredom. Not getting to go outside much. I wasn't allowed outside at all until a month had gone by. Not ever knowing when I would get out. Seeing most of the women on my ward come back from electroshock. Hearing them scream while in seclusion or restraint. Terrified the whole time that I would get shock. [9]

In my community organizing work, I have also come across positive stories that give me hope, including the history of allies who may be risking their professional careers by calling for deep change in mental health care. These dissident mental health providers have taught me that there is an antidote to the silencing caused by the power imbalance in mental health care, and that is the power of civil dialogue. A friend of mine who was a psychiatrist, Loren Mosher (1933–2004), did much to show me during the last years of his life what an ally within the psychiatric profession could do to help psychiatric survivors [10].

As I learned more about Loren's past, I found out that at the same time I made my vows in solitary confinement in a psychiatric institution as a Harvard student to become an activist, Loren was one of the national leaders in the USA on mental health care, and held a position as Chief of the Center for Studies of Schizophrenia at the US National Institute of Mental Health [11]. We did not know each other at that time, but Loren was attempting to prevent the type of mental health system bullying I was experiencing.

Loren helped create 'Soteria House' which, from 1971 to 1983, provided evidence that promoting caring relationships with people in crisis in a non-coercive, non-medical environment can produce positive outcomes [12]. As courageous as creating an alternative centre was, Loren did far more. Like civil rights activists who inspired our social change movement, Loren stood with us psychiatric survivors and spoke out. He agreed that activism to protest oppression was necessary, and he often did this with wit and humour. In a now-famous letter, Loren publicly resigned from the American Psychiatric Association. He wrote in the first paragraph 'The major reason for this action is my belief that I am actually resigning from the American Psychopharmacological Association. Luckily, the organization's true identity requires no change in the acronym.' [13]

Trauma meted out by the mental health system may naturally lead to anger and distrust in some psychiatric survivors. To whom can we turn for help, when it is the healing profession itself that we feel has most wounded us? Unfortunately, far too often we take this anger out on each other, or on our allies. Loren drew the line at tolerating personal abuse or unethical behaviour from anyone, including psychiatric survivors. Loren also realized that taking public action side by side with us, as uncomfortable as that might be, was important for transforming the system, and for our personal recovery from abuse. Loren spoke to the media, to his fellow psychiatrists, to the World Psychiatric Association, to the public, to anyone about our human rights, and what he saw as the truth about the failures of mental health care today.

I keep the example of Loren Mosher in mind when I am getting to know a sympathetic provider in the mental health field. I try to determine if this professional has taken any public action, no matter how modest, to better and humanize that system. Many mental health practitioners privately tell me, to paraphrase, 'Within my office, in my practice, behind closed doors, I provide clients with voluntary, gentle care that respects self-determination. But I never speak out publicly.' I feel this is a missed opportunity. Psychiatric survivors need their provider to be more than what I call a 'closed-door ally'. To such providers I say, I cannot tell you what way of breaking the silence is most aligned with your personal principles and inspiration. However, I can say that to be a truly great ally like Loren Mosher one must be willing to protest openly in some way, and break the silence about the emergency of human rights violations inherent in coerced psychiatric care.

To psychiatric survivors I say, if you have rage over the trauma caused by mental health system abuse, I understand. I do, too. But remember that Martin Luther King, Jr said 'Human salvation lies in the hands of the creatively maladjusted.' [14] I am not perfect, but I try to find a safe place to express my unfocused anger with trusted peers who understand. However, when taking public action with one another, it is in our individual and collective best interests to creatively channel our passion into unity. In my over-three decades of experience, I've seen division amongst psychiatric survivors be one of the main preventable obstacles to the nonviolent revolution in mental health care that I feel is so desperately needed.

By coincidence, all of the personal stories I have cited so far are by present and former board members of MindFreedom International. On our board of directors, we have had survivors of coerced psychiatric abuse such as Chamberlin, Foner and Chabasinski; but we have also had mental health professionals such as Mosher. All have bravely spoken out in their own ways for a complete overhaul of our mental health care system.

Activists in other movements on behalf of extremely disempowered constituencies have discovered the power of combining resistance with civil dialogue with opponents. Mahatma K. Gandhi, for example, believed that finding reconciliation was necessary to build a sustainably peaceful society. One of Gandhi's most memorable traits was his interest in seeking to convert his opponents by engaging in dialogue [15]. As Gandhi himself put it, 'A nonviolent revolution is not a program for the seizure of power. It is a program for the transformation of relationships ending in a peaceful transfer of power.' [16] In fact, I feel this mutual respect is at the root of peer support, which has helped so many of us receiving mental health care find a path to sustained, full recovery following severe mental and emotional problems. The moral principle of mutual respect applies not only to peer support between people diagnosed with psychiatric disorders who are in mental health care; this principle applies to everyone, including those who have taken away our rights. While I seek to change the laws so that coerced psychiatric procedures are an illegal, criminal offence, punishable in severe instances with fair prison sentences, I do not wish inhumane retribution or revenge on anyone.

One of the most prominent national psychiatric survivor activists in the USA is Pat Risser, and he described the power of mutual support to me this way:

> Every time I'd tell a psychiatrist or therapist that I was suicidal, I'd get locked up, forcibly drugged, secluded and restrained. I survived over 20 hospitalizations including one hellish stay at a State hospital. Nothing, and I repeat, *nothing* that the system did to me or for me worked. Everything they tried just seemed to make matters worse. The only thing that helped was being accepted as a 'real' person by my fellow patients. Eventually, I realized that I could receive that sort of support without going into a hospital [17].

Just as Pat found the beginning of his own recovery by being acknowledged as a 'real person', so I believe dialogue between representatives of psychiatric professional organizations and psychiatric survivor organizations may help each see that the other is a real person.

It is difficult to express how the intrusion of coerced psychiatric care can feel so shattering to our very being that we may keep silent about our stories of mental health abuse. Dialogue can at least help instruct and warn others about the true cost of such violent and counterproductive mental health coercion. Repeatedly, in preparing this chapter I have reflected back to times in history when other enormous power imbalances have been addressed in dialogue. I recall a famous dialogue I read about from ancient days, recounted by Thucydides in his *History of the Peloponnesian War* [18]. I am referring, of course, to the dialogue between representatives of the inhabitants of the small, vulnerable island nation of Melos, and Athenian negotiators who demanded that Melians immediately submit and become Athenian allies in the imperial contest with Sparta. Plaintively, the Melians suggested a way to peace near the end of the dialogue, saying, 'We invite you to allow us to be friends of yours and enemies to neither side, to make a treaty which shall be agreeable to both you and us, and so to leave our country.' The Melians predicted in the dialogue that if Athens continued to choose crushing brutality in dealing with small nations like Melos, then Athens would eventually lead itself to self-destruction. While the Athenians did indeed decimate the population of the Island of Melos, in the long run the Melian prediction came true, Athens fell, and the wisdom of Melos rings down through history.

So, too, the often-ignored call for dialogue by representatives of organizations of psychiatric survivors is about more than venting over the harm caused to our constituency by coerced psychiatric human rights violations. We are in fact making a call to psychiatric professionals to redeem their own humanity, and to save their own profession. Perhaps a more contemporary example of the power of such dialogue may be the way South Africa has attempted to heal from Apartheid by having Truth and Reconciliation Commissions [19]. Of course, Apartheid first had to be made illegal for any lasting healing to occur.

Another example of the purpose of dialogue may be the way survivors of abuse while children within the Catholic Church have organized to call for systemic change throughout that religion's hierarchy. Too often we hear from leaders of the mental health industry that human rights violations by psychiatric professionals are the result of a 'few bad apples'. But the stunning silence of psychiatric professional organizations failing to address these human rights issues, or to even agree to dialogue about them, threatens to doom the credibility and future of the entire psychiatric profession itself. Dialogue is for the benefit of both sides of a power imbalance, because the humanity of both sides is robbed by that imbalance. Though I'm not a psychologist, I know that reward is more powerful than punishment. Therefore, in subtle ways those on the dominant end of an unfair power imbalance may be more trapped in this toxic relationship than those who are oppressed.

In June 2007, several organizations representing mental health consumers and psychiatric survivors did unite to engage in a hopeful dialogue with the World Psychiatric Association (WPA). The European Network of (ex-)Users and Survivors of Psychiatry, World Network of Users and Survivors of Psychiatry, and MindFreedom International, issued a statement, 'Declaration of Dresden Against Coerced Psychiatric Treatment', with the intent of making clear a coordinated position on force and psychiatry at the World Psychiatric Association Conference, *Coercive Treatment in Psychiatry: A Comprehensive Review*, that was held in Dresden, Germany [20].

In part, this 'Declaration of Dresden Against Coerced Psychiatric Treatment' stated,

> Our organizations are in a unique position to speak on this issue because we have experienced forced psychiatry and know the damage it has done to our lives and those of our members, colleagues, and friends. . . We believe that people who have been coerced by psychiatry have a moral claim to making the definitive statement concerning such coercion. We stand united in calling for an end to all forced and coerced psychiatric procedures and for the development of alternatives to psychiatry.

The united statement emphasized the historic nature of a treaty adopted in January 2007 by the United Nations General Assembly, entitled *Convention on the Rights of Persons with Disabilities* [21]. MindFreedom International is an NGO with United Nations Consultative Roster Status, and therefore our delegation, mainly composed of people who had personally experienced coerced psychiatric care and headed by our board president Celia Brown, worked side by side with hundreds of disability advocates from all over the world inside UN headquarters in New York City to craft and pass this binding international treaty. The Declaration of Dresden refers to this treaty, stating:

> We all have a right to refuse psychiatric procedures, since this Convention recognizes the right to free and informed consent with no discrimination based on disability. Even

> more important, the Convention guarantees to people with disabilities the right to make our own decisions (legal capacity) on an equal basis with others, and requires governments to provide access to non-coercive support in decision-making, for those who need such support.

The very specific human rights violation of involuntary electroshock was explicitly cited in the Declaration of Dresden, because opposition to this extreme practice unites many mental health organizations, including the World Health Organization [22]. From the Declaration:

> We note that the World Health Organization (WHO) has stated its opposition to all involuntary electroshock, which is also known as electro-convulsive therapy (ECT). Involuntary electroshock is increasing internationally, including in poor and developing countries where it is most likely to be used without anesthesia. In particular, we call for the abolition of involuntary ECT in every country.

The Dresden statement also discusses the interest of international health bodies in developing self-help approaches for people in emotional distress that are less discriminatory. The statement read,

> Organizations of people who have experienced psychiatric treatment have taken the lead in developing self-help programs that are based on equality and choice, rather than on coercion, and have been successful in helping people lead integrated lives in the community. We know that healing can only occur when people are respected as humans with free will and when there are alternatives beyond psychiatry which are based on ethical approaches, which see the whole person, and which support recovery, while force makes recovery impossible.

The Declaration of Dresden also singles out involuntary outpatient commitment, the practice discussed above in which court orders can require individuals who are living out in the community in their own homes to take prescribed psychiatric medication against their wishes. States the Declaration,

> We note that in many countries of the world, there is an increasing use of forced psychiatric procedures, including court ordered treatment which requires that people living in their own homes take psychiatric drugs against their will or lose their freedom. This practice is a violation of our human rights as set forth in the UN Convention.

Those of us who worked on the Declaration of Dresden realized that our vision of eliminating and replacing psychiatric coercion is many years away, but we felt compelled to at least state our dream. We ended the statement by saying,

> We invite all supporters of human rights to join and support us in demanding a world free of forced and coerced psychiatric procedures, and we call for adequate funding and support for voluntary self-help services and for alternatives to psychiatry which respect our humanity and dignity.

In the Dresden event, I personally felt hope that there may be more extensive and ongoing dialogue between representatives of mental health professional organizations, and psychiatric survivor organizations. We held informal meetings and a news conference with leaders from psychiatric professional organizations. The only discordant note was that apparently some representatives of pharmaceutical exhibits had objected to our style of grassroots activism in the conference. For whatever reason, as of this writing, I unfortunately must report that our offers for mediated dialogue following Dresden have generally not been accepted.

As a community organizer, it helps me to understand how a Declaration of Dresden can apply to real human beings in real circumstances. In my own workshop in Dresden, I suggested that, to assist in communicating with the public, it would be helpful to describe human rights violations involving coerced mental health care as falling generally into three categories: Force, Fraud and Fear. I'll provide here a few examples of each.

12.3 Forced psychiatric procedures over our expressed wishes

A contemporary example of forced psychiatry has taught all of us at MindFreedom International valuable lessons. I was in the MindFreedom office in October 2008 when we were phoned by an individual, Ray Sandford of Minnesota, who claimed that he was receiving ongoing, involuntary, outpatient electroshock procedures against his expressed wishes, on a weekly basis. We immediately investigated, because I had never heard of involuntary outpatient commitment being used for coerced electroshock of an individual living out in the community.

I contacted Ray's mental health workers and his mother, and read his court records. I found that there was no secret about it. Ray lived in a small group home in the Minneapolis area. Each Wednesday morning he was awoken early and escorted several miles to a nearby hospital where he received electroconvulsive therapy, and sent home until the next week. He had become determined to stop his regular, coerced outpatient electroshocks. However, while I considered Ray's abuse to be unconstitutional, all the proper Minnesota court orders gave the mental health authorities the legal power to give Ray this coerced electroshock each and every week [23].

It was a moving experience to speak to Ray on the phone before several of these involuntary electroshocks over his expressed wishes. He somehow managed to stay calm on the phone, and expressed in a reasoned but poignant way why he didn't want to have another coerced electroshock. He complained about memory problems he attributed to the procedures. He also objected to other aspects of the procedure, including being forced to undergo anaesthesia. Mainly, he reasonably found forced electroshock to be 'scary'.

We model MindFreedom International's work on the much more famous human rights organization, Amnesty International, so we quickly fashioned a human rights alert to distribute internationally to tens of thousands of concerned people, many of whom began responding immediately by contacting the Governor of Minnesota, and by forwarding the alert to others. We expected that as soon as the matter was brought to light, Ray's forced electroshocks would end. However, even though alert after alert went out, and outraged citizens would contact more and more mental health authorities and elected officials, Ray's involuntary electroshock continued. After further investigation we found a network of more than 30 agencies and services that received public funding and were mandated to help Ray, including protecting his rights. While a few agencies were assisting Ray in his efforts to end his electroshock, many of these 30 agencies were not supporting his efforts to win his human rights at all. Some agencies were in fact passionately fighting in court to continue Ray's forced electroshocks [24]. In a public relations disaster for the mental health system, one of Ray's forced electroshocks – which would turn out to be his last – was on 15 April 2009, which is USA tax day. While I do not have a scientific survey, my impression is that taxpayers generally do not appreciate their scarce resources being used to take a fellow citizen from his home over his objections for regular forced electroshocks.

We redoubled our efforts. Several of us, including myself, flew to Minnesota for peaceful protests. Ray received more attention, including national publicity [25]. Once we convinced members of the public, we quickly were able to outnumber the network of agencies surrounding Ray. We helped Ray to replace his attorney, psychiatrist and guardian. Finally, the forced electroshock ended and his rights were enforced. It is important to note that, throughout his campaign, Ray was not a mute or incoherent individual who was receiving electroshock. Ray was consistently outspoken and clear about why he did not want to receive involuntary electroshock, and he was consulted throughout on the campaign.

We had been told that Ray could not survive without his weekly involuntary electroshock. However, as I write this, it's been over one year since Ray's last electroshock. He calls me at the office about once or twice a week to check in, and I consider him a friend. I remind Ray that every day that he does well, every day that he thrives, he disproves the claim that he absolutely had to have coerced electroshock to survive.

We learned from Ray's victory. We learned that human rights violations like this were systemic, and so would require a systemic and organized nonviolent direct response mobilizing hundreds or even thousands of individuals and groups. Once more, we also found that once the public was informed with convincing evidence of such an outrageous violation as forced outpatient electroshock, we received astounding levels of support. I have found the vast majority of the public – both conservative and liberal – express revulsion and disgust about the continued existence of involuntary electroshock over the expressed wishes of the subject. The fact that such a violation can continue to this day internationally, including throughout the USA, shows that mental health system endorsement of principles, such as human rights, empowerment, peer support and advocacy, may not be entirely convincing to psychiatric survivors.

I feel that all involuntary psychiatric procedures can lessen an individual's level of dignity and self-determination, which are necessary resources for long-term sustained recovery. All involuntary psychiatric procedures undermine an individual's trust with their provider and the community, and this trust ought to be a cornerstone in rebuilding the relationships we all need for mental and emotional well being. All involuntary psychiatric procedures can feel unjust, because an individual is losing their liberty due to a psychiatric diagnosis, rather than because of violating a law created by duly elected representatives that is fairly applied to everyone equally.

However, especially troublesome is the intersection between involuntary psychiatric treatment, and particular procedures which – by their very nature – are intrusive and potentially irreversible. In other words, forced counselling may be humiliating, but one can choose to ignore the mental health counsellor. For example, if a judge offers a convicted drunk driver an educational programme as part of creative sentencing, this is part of due process, and is not coerced psychiatric care. However, procedures such as electroshock, psychiatric drugging and psychosurgery cannot be ignored, and therefore are especially problematic, even when administered to an individual who has been deprived of their liberty because of violating a criminal law. In other words, coerced electroshock, psychiatric drugging and psychosurgery are always wrong, even for individuals in the criminal justice system, because they are inherently cruel and unusual punishment.

Our social change movement is not alone in expressing opposition to all involuntary psychiatric procedures. We have especially found support amongst those working for the human rights of people with disabilities. The US National Council on Disability (NCD) is an independent federal agency empowered by law to provide policy recommendations to the President and Congress on issues involving disability. As one of the highest authorities associated with the US federal government addressing disability matters, the NCD produced a special report in 2000 about coercion in the mental health system, holding a unique public hearing and gathering evidence from psychiatric survivors. The report is entitled *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* [26].

In the Executive Summary, the NCD describes the process used to create this groundbreaking report:

> NCD heard testimony graphically describing how people with psychiatric disabilities have been beaten, shocked, isolated, incarcerated, restricted, raped, deprived of food and bathroom privileges, and physically and psychologically abused in institutions and in their communities. The testimony pointed to the inescapable fact that people with psychiatric disabilities are systematically and routinely deprived of their rights, and treated as less than full citizens or full human beings.

NCD produced 10 'core recommendations'. The first recommendation provides a hopeful vision on the subject of coercion and psychiatry:

> Laws that allow the use of involuntary treatments such as forced drugging and inpatient and outpatient commitment should be viewed as inherently suspect, because they are incompatible with the principle of self-determination. Public policy needs to move in the direction of a totally voluntary community-based mental health system that safeguards human dignity and respects individual autonomy.

The NCD report also spelled out their reasons for this courageous stand:

> Involuntary treatment is extremely rare outside the psychiatric system, allowable only in such cases as unconsciousness or the inability to communicate. People with psychiatric disabilities, on the other hand, even when they vigorously protest treatments they do not want, are routinely subjected to them anyway, on the justification that they 'lack insight' or are unable to recognize their need for treatment because of their 'mental illness.' In practice, 'lack of insight' becomes disagreement with the treating professional, and people who disagree are labeled 'noncompliant' or 'uncooperative with treatment.'

NCD showed great sensitivity and empathy about why we often do not hear from survivors of psychiatric abuse in our society:

> After years of contact with a system that routinely does not recognize their preferences or desires, many people with psychiatric disabilities become resigned to their fate and cease to protest openly. Although this is described in the psychiatric literature as 'compliance,' it is actually learned helplessness (also known as 'internalized oppression') that is incompatible with hope and with the possibility of recovery.

NCD said that, according to their public hearing, involuntary psychiatric interventions often harm people emotionally, which is the direct opposite of the goal of mental health care:

> The overwhelming amount of testimony concerned the harmfulness of involuntary interventions on people's sense of dignity and self-worth, and, further, contended that such interventions were seldom helpful in assisting people either with their immediate problems or with their long-range ability to improve their lives. NCD heard numerous eloquent pleas for services that were responsive and respectful, and which allowed recipients the same rights and freedoms other citizens take for granted.

The unique nature of trauma from involuntary psychiatric procedures means that it is difficult to elicit public statements from those who have experienced it. In other words, to whom does one turn for help, when one has reason not to trust the helpers? This conundrum can silence those who need to speak out about the coercion they have experienced.

From the NCD report,

> It is important to keep in mind that the hearing was one of the rare opportunities for people labeled with psychiatric disabilities themselves to be the major voice in a government-sponsored inquiry into mental health issues. It is common for mental health policy discussions never to mention words such as 'involuntariness' or 'force,' because these topics are seldom addressed except by people who have suffered because of them. In fact, there seems to be a tacit acceptance among policymakers and the media that people labeled with psychiatric disabilities 'need' to be forced 'for their own good,' and the question of whether such force belongs in a system of medical treatment rarely is systematically examined.

12.4 Fraud – coercion by misinformation

As in any complex field, there is ongoing, vigorous debate within the mental health profession about the scientific validity of many psychiatric practices and theories. In the case of coerced psychiatric procedures, this uncertainty and ambiguity becomes troublesome. A licensed mental health provider has been granted an enormous amount of authority by society. One could argue that in coerced psychiatric procedures, some of the most powerful individuals in our society have authority over some of the most disenfranchised, and discredited citizens. Because of this power imbalance, the veracity of claims by mental health professionals ought to be held to the highest scientific standards, because an error may destroy what many of us hold most precious: our liberty.

One of the most devastating experiences for me in my mental health care was misinformation. While being held down on a mattress and forcibly injected with a psychiatric drug was dramatic and degrading, the experience that almost broke my spirit was when, as I discussed above, a respected mental health professional provided to me disempowering disinformation about my psychological issues. I remember sitting down during my fifth psychiatric institutionalization with a Harvard psychiatrist in the recreation room of our ward. He looked me in the eye and told me he was certain that I had a genetically caused, incurable chemical imbalance, and therefore – just as a diabetic needs insulin – I would absolutely have to take powerful prescribed psychiatric medications such as neuroleptics for the rest of my life. Because of support from family, friends, advocacy groups and better mental health professionals, I was able to become sceptical of the claims of this psychiatrist. However, I well remember how close he came to convincing me to become a lifetime mental patient. I believe this psychiatrist was well meaning, but whether intentional or not, his misinformation amounted to fraud. His immense authority, combined with his unscientific message of hopelessness, was in fact a dangerous type of coercion.

I will give just a few examples of mental health controversies where I believe unscientific information may be misleading individuals in mental health care to make decisions different from those they would make if they were offered full and complete information.

1. Psychiatric diagnosis

One of the common legal requirements to justify a coerced psychiatric procedure is a psychiatric diagnosis. However, as a lay activist, I watch in amazement as leaders within the psychiatric industry cannot agree about the future of psychiatric diagnosis itself, as the American Psychiatric Association prepares the next edition of their highly influential *Diagnostic and Statistical Manual* (DSM), which influences psychiatric diagnosis internationally.

In a column entitled 'It's not too late to save "normal"', published in the *Los Angeles Times*, Allen Frances, MD, issues a clarion call of warning [27]. Dr Frances chaired the American Psychiatric Association (APA) task force that created the fourth edition of the *DSM* which was published in 1994. He wrote,

> I learned from painful experience how small changes in the definition of mental disorders can create huge, unintended consequences. Our panel tried hard to be conservative and careful but inadvertently contributed to three false 'epidemics' – attention deficit disorder, autism and childhood bipolar disorder. Clearly, our net was cast too wide and captured many 'patients' who might have been far better off never entering the mental health system.

What is even more remarkable is the way Dr Frances directly challenges those working on the next version of the DSM. Referring to a draft that the APA posted online, Dr Frances said,

> [it] is filled with suggestions that would multiply our mistakes and extend the reach of psychiatry dramatically deeper into the ever-shrinking domain of the normal. This wholesale medical imperialization of normality could potentially create tens of millions of innocent bystanders who would be mislabelled as having a mental disorder. The pharmaceutical industry would have a field day – despite the lack of solid evidence of any effective treatments for these newly proposed diagnoses.

I have to wonder, how accurate is a psychiatric diagnosis when there is such fierce struggle between those who have been the leaders for creating these diagnoses? No elected officials are involved in discussing, creating and voting upon the list of behaviours in the DSM, even though these diagnoses often have the force of law, and could mean the difference between freedom and liberty. 'We the people' have no direct representation in the decisions that create this powerful guideline for our behaviour.

2. **Chemical imbalance**

It is far beyond the scope of this chapter to explore, confirm, refute or even adequately explain some of the current theories in mental health care today. However, I have heard many statements over the years from leaders of various mental health organizations that major psychiatric disorders such as schizophrenia and bipolar are 'biologically based'.

Readers may find it relevant to know about a nonviolent direct action that I and a number of other MindFreedom International activists took together in 2003 on this topic: a hunger strike. Journalist Robert Whitaker has suggested that our hunger strike was a model in how individuals may question the current mental health system [28]. Our Fast for Freedom in Mental Health had a simple demand of the American Psychiatric Association: to produce evidence of this 'biological basis'.

We asked: 'Has science established, beyond a reasonable doubt, that so-called "major mental illnesses" are biological diseases of the brain?' We also asked: 'Does the government have compelling evidence to justify the way it singles out for its primary support this one theory of the origin of emotional distress and of pharmaceutical remedies for its relief?' [29].

For example, we requested evidence for a physical diagnostic exam – such as a scan or test of the brain, blood, urine, genes and so on – that can reliably distinguish individuals with these diagnoses (prior to treatment with psychiatric drugs), from individuals without these diagnoses. We refused to eat until we received a reply from the American Psychiatric Association and other psychiatric organizations, and the nonviolent conflict resulted in significant national media attention [30].

To its surprising credit, the American Psychiatric Association entered into a helpful and extensive back and forth written dialogue with our MindFreedom Scientific Panel. Several of us hunger strikers also met with the elected APA president. In the end, the APA did not claim to have any scientific evidence for a biological basis for psychiatric disorders. The concluding statement by the MindFreedom Scientific Panel on 15 December 2003 raised a final question that is especially applicable to this chapter:

> The hunger strikers asked the APA for the 'evidence base' that justifies the biomedical model's stranglehold on the mental health system. The APA has not supplied any such evidence, which compels the scientific panel to ask one final question: on what basis does society justify the authority granted psychiatrists, as medical doctors, to force psychoactive drugs or electroconvulsive treatment upon unwilling individuals, or to incarcerate persons who may or may not have committed criminal acts? For, clearly, it is solely on the basis of trust in the claim that their professional acts and advice are founded on medical science that society grants psychiatrists such extraordinary authority.

3. Long-term effects of psychiatric medications

As I've explained, I personally came very close to believing that I needed to be kept, these past 34 years, on continuous neuroleptic psychiatric medications, also known as antipsychotics. Therefore, the long-term impact of this particular family of medications is especially relevant to my own life. In the last few years, mainstream science has used modern research, brain scans, animal studies and autopsies to study whether long-term neuroleptics may be inducing structural brain change, including to the brain's frontal lobes, which are linked to higher-level functions [31]. It is beyond this chapter's scope and my expertise to summarize and analyse these findings here. I will, however, quote from the abstract of just one recent study, which concluded:

> Some evidence points towards the possibility that antipsychotic drugs reduce the volume of brain matter and increase ventricular or fluid volume. Antipsychotics may contribute to the genesis of some of the abnormalities usually attributed to schizophrenia. [32]

Attorney James Gottstein, who directs the public interest law firm PsychRights, is utilizing reviews of scientific studies about the impact of neuroleptics on the brain in his courtroom battles on behalf of clients who are attempting to prevent their involuntary psychiatric drugging [33]. In my work as a mental health advocate, I have never seen a written informed consent for neuroleptic psychiatric drugs which explains this finding, which is especially relevant to the controversy of coerced psychiatry. When a psychiatric procedure can be shown to induce significant changes to the structure of the brain, this means that enforcing the treatment raises special ethical issues similar to the older controversy of involuntary psychosurgery.

We frequently hear that coerced psychiatric procedures are justified because we lack insight into our condition, and that we don't understand the necessity of our treatment. However, I find that many patients, families, elected officials, the media and even many mental health professionals are often not adequately informed by the medical community about such urgent controversies as the impact of long-term neuroleptics on our brains. In fact, in my informal estimation, many psychiatric survivor activists are more informed about these scientific matters than some busy mental health professionals.

12.5 Fear – one choice is no choice

While force and fraud are more obvious ways to gain compliance without the true full informed consent of the individual, there is another category of coercion that I would consider to be the most common, which I sum up as *fear*, fear that one cannot find an alternative to the few mental health approaches that tend to be offered, which seem to mainly be medical model approaches such as psychiatric drugs.

MindFreedom International and I are pro-choice about personal health care decisions, and many of our members choose to take prescribed psychiatric drugs. Others like me do not. But we are united in speaking out about the immense power and domination of the psychiatric drug approach that seems to squeeze out other choices. We feel there are humane, effective, voluntary non-drug approaches that are often not readily made available to people who need that help. For example, the book *Alternatives Beyond Psychiatry*, co-edited by psychiatric survivor Peter Lehmann and psychiatrist Peter Stastny, brings together 61 authors from all over the world to examine more empowering and humane psychosocial options to help individuals seeking mental health care, other than coerced psychiatric procedures based on a primarily medical model [34]. When an individual in crisis is offered only one type of mental health care, this is a kind of Hobson's choice. That is, offering one choice is not really a choice.

In my hometown of Eugene, Oregon, the City of Eugene Human Rights Commission chose to address human rights in mental health as a priority issue for several years, and one result was the crafting of a resolution on the topic of choice in mental health as a human right. On 26 October 2009, the City Council of Eugene unanimously passed Resolution 4989, which states that the availability of more non-drug options in mental health care is the right of every citizen [35]. I conclude with the text of this unique resolution, below, because I find it to be a hopeful example of democracy beginning to get more hands-on and proactive about mental health care, rather than to defer that authority to a fairly small group of medical professionals. With a more empowered and informed public, perhaps we can address and end the immense power imbalance between those on the receiving end of coerced psychiatric procedures, and mental health providers.

RESOLUTION NO. 4989

A RESOLUTION AFFIRMING THE CITY'S COMMITMENT TO HUMAN RIGHTS AND MENTAL HEALTH CARE.

The City Council of the City of Eugene finds that:

A. The City Council of the City of Eugene recognizes that the diversity of our population is vital to our community's character, and that we have a long tradition of protecting and expanding human rights and civil liberties protections for all of our residents, including persons with all types of disabilities.

B. U.S. Courts have affirmed a number of rights for people diagnosed with mental disabilities. At the national level, the right to choose to live in the least restrictive environment that is reasonably available has been affirmed. At the state level, a number of courts have affirmed a person's right to refuse psychotropic medications, even when the state has a "compelling interest" in providing treatment, if less intrusive, effective treatment alternatives exist. These decisions are consistent with the principle that all people have the right to lives free of unnecessary restrictions and intrusions.

C. Many people determine that psychiatric medications are quite helpful for their mental and emotional conditions, and are grateful to have the opportunity to take them. Others find medications to be harmful to their health, unhelpful and/or excessively intrusive and problematic. When people seek treatment and are offered medication as the only treatment option, they may feel coerced into choosing that option. Many of the medications currently provided are typically associated with significant medical risk, are often experienced as subjectively harmful, and their long-term effectiveness remains controversial. Furthermore, there are widely researched psychosocial alternative treatments likely to be at least as effective for many, with fewer harmful effects.

D. Many mental health problems are caused by trauma and human rights violations, such as child abuse, war, racism, lack of housing and economic opportunities, domestic violence, and others. A key element in any kind of trauma is the denial of choice. When people who have been traumatized are denied choices in recovery, an effect may be retraumatization.

E. Serious psychiatric disorder is often thought of as inevitably a permanent condition requiring a lifetime of medication, however research shows that a substantial fraction of those with even the most serious diagnoses do fully recover, eventually not requiring treatment. Treatment choices, designed to foster rehabilitation and recovery, which include working, living, and participating in the life of the community, have been shown to increase such recovery.

NOW, THEREFORE, BE IT RESOLVED BY THE CITY COUNCIL OF THE CITY OF EUGENE, a Municipal Corporation of the State of Oregon, as follows:

Section 1. All mental health service providers within the City of Eugene are encouraged to incorporate self determination and consumer choice as much as possible, with accurate information provided to consumers and to families about those choices. Special emphasis should be placed on providing diverse alternatives in treatments, including non-drug alternatives, whenever possible.

Section 2. All mental health service providers within the City of Eugene are urged to offer a full range of choices designed to assist in complete recovery.

Section 3. This Resolution shall become effective immediately upon its adoption.

The foregoing Resolution adopted the 26 day of October, 2009.

12.6 Conclusion – offering dialogue and calling for demonstrations

Those of us who have allied ourselves with the less powerful side of the imbalance inherent in coerced psychiatric procedures need to learn from other social change movements throughout history who have turned to nonviolent direct resistance through creative civil disobedience. I realize that some in the psychiatric profession who say they support our concerns may oppose the idea of protest.

In his famous letter from the Birmingham Jail on 16 April 1963, Martin Luther, Jr, wrote this to those who cautioned him to slow down his protests:

> You deplore the demonstrations taking place in Birmingham. But your statement, I am sorry to say, fails to express a similar concern for the conditions that brought about the demonstrations. I am sure that none of you would want to rest content with the superficial kind of social analysis that deals merely with effects and does not grapple with underlying causes. It is unfortunate that demonstrations are taking place in Birmingham, but it is even more unfortunate that the city's white power structure left the Negro community with no alternative. [36]

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