Organizing Guide for Psychiatric Survivors
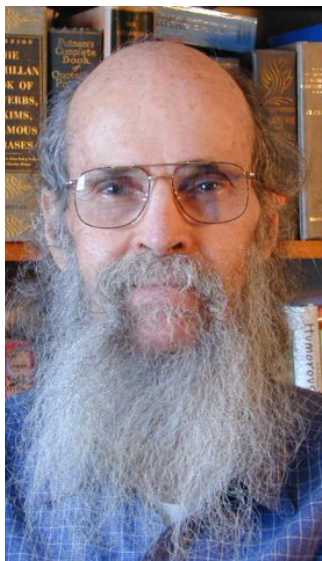
This handbook is dedicated to the memory and legacy of Leonard Roy Frank who dedicated his life to ending psychiatric oppression.

"Mystification is the psychiatrist's defense against the danger of being found out."
—Leonard Roy Frank

This project honors everyone's potential to be a leader and an activist, even those in the back wards of the most restricted psychiatric facilities. This project aims to meet everyone where they are at, no matter their circumstances or abilities.

Published February 2019, Eugene, OR

Cover art by Nancy Bright, "The Passage"
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Organizing Guide for Psychiatric Survivors

MindFreedom International is a nonprofit organization that unites dozens of sponsor and affiliate grassroots groups with hundreds of individual members to win human rights and alternatives for people labeled with psychiatric disabilities.

This handbook was made possible with generous support from the Foundation for Excellence in Mental Health as a part of MindFreedom International's "Voices for Choices" project. It is primarily intended as a guide for psychiatric survivors/activists, but a segment is devoted to mitigating harm and protecting the rights of the most disempowered among us: the hundreds of thousands of forcibly treated individuals whose voices are routinely silenced.

This handbook is downloadable on the website of **MindFreedom International** at mindfreedom.org/organizing-handbook. If you or someone you love is unhoused, locked up in a psychiatric facility, jail, or prison, and lacks access to a computer, a limited number of hard (free) copies are available by request. Send requests to: office@mindfreedom.org.

While proponents of force and coercion bemoan the reduction of psychiatric "beds" in the US from a high in 1956 of 560,000 to about 100,000 today, these "advocates" rarely engage with the people who have survived forced drugging, shock, restraints, seclusion, institutionalization, etc. while occupying such "beds." If they did, they would understand why MindFreedom International and other independent psychiatric survivor organizations are calling for a full-scale revolution in the mental health system. We hope this handbook will empower you and bring out the revolutionary in you!
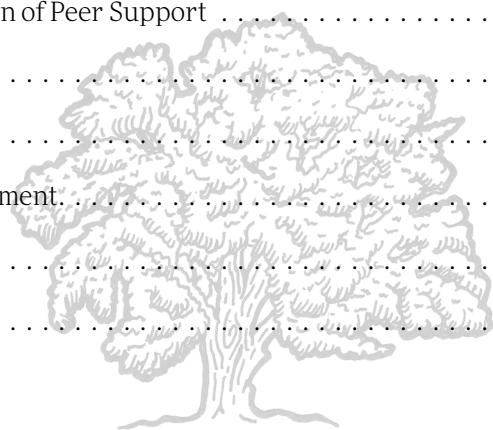
Table of Contents

Illustrations in this guide were drawn by Daniel Young. Nut, Tree, and Grove illustrations by Mikayle Stole. Design of the handbook provided by Mikayle.com. Cover art by Nancy Bright.

TREE

GROVE

NUT

"An oak tree comes from a single nut that stood its ground."
–Author Unknown

This handbook is divided into three sections: Nut, Tree, and Grove. In the Nut section, topics pertain to the individual. Individuals in distress who receive a psychiatric diagnosis are at risk of iatrogenic harm and disempowerment, especially those who are treated by force and coercion. Learn ways to protect yourself and mitigate harm. Standing your ground starts with knowing that something is deeply wrong with "healers" who routinely control distressed individuals with threats and intimidation, treating them like naughty children, using restraints, solitary confinement, shock, forced drugging, etc. even when no crime has been committed!

In this guide, leadership is defined as the ability to hold one's ground, not an aptitude that one is born with. Like nuts, we are all endowed with the potential for positive growth. All of us long to evolve and be a part of something greater than ourselves. The Tree section features alternatives to the medical model. Lean how to help individuals who experience mental and emotional challenges flourish by welcoming them into supportive communities which honor nondrug/nonforce alternatives. Learn how to find, join, and build communities that empower people by modeling egalitarianism, curiosity, mutualism, and interdependence. Learn about the importance of honoring a diversity of voices, perspectives, and abilities. Learning to work effectively in groups is personally rewarding and a pathway to wellness.

The Grove section pertains to the psychiatric survivor's movement, learning to engage with other movements for social change. Psychiatric survivors have a lot to teach activists from other movements for social change and vice versa. By teaching mental health activists how psychiatric oppression is related to other forms of oppression, the needed revolution in mental health will gain new allies and greater momentum.

Overview of Handbook

NUT

"An oak tree comes from a single nut that stood its ground." Personal empowerment is how nuts learn to stand their ground. Disempowering messages are often internalized by psychiatrized individuals and can be crushing. Questioning what the "experts" say about you and finding your voice is the key to unleashing your personal power.

TREE

An oak tree mitigates the effects of excess carbon in the atmosphere, providing oxygen, shade, wind protection, wildlife habitat, nutrients, beauty, and inspiration. In this section, readers learn ways of flourishing by building community, pursuing service, giving/receiving peer support, and engaging in activism.

GROVE

This section is dedicated to the wealth of knowledge learned by pioneers in the psychiatric survivor's movement. It is about how this movement intersects with other movements for social change, and it includes tactics and strategies for effective activism.

Diagnosis and the DSM

> ## "The relevant question in psychiatry shouldn't be what's wrong with you but what happened to you."
>
> *–Jacqui Dillon*
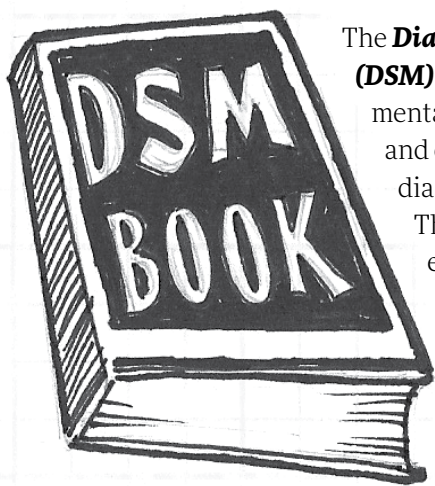
The ***Diagnostic Statistical Manual (DSM)*** is a standard classification of mental disorders used by mental health and other health professionals for diagnostic and research purposes. The **DSM-5** is the fifth, most recent edition.

DSM and **DSM-5** are trademarks of the American Psychiatric Association, which receives a substantial portion of its annual operating revenues from **DSM** sales.

In 1952, the **DSM-1** listed 106 mental health disorders. The **DSM-3**, from 1980, listed 265, and the current **DSM-5** has 297.

The **DSM** came into nearly universal use, not only by psychiatrists, but by insurance companies, hospitals, courts, prisons, schools, researchers, government agencies, and the rest of the medical profession. Its main goal was to bring consistency (usually referred to as "reliability") to psychiatric diagnosis; that is, to ensure that psychiatrists who saw the same patient would agree on the diagnosis.

"Although in recent years, much has become known about the harm caused by Pharma and by involuntary commitment and forced treatment, surprisingly few people have seemed to notice that everything bad that is done to patients in the mental health system begins with psychiatric diagnosis."—Paula Caplan,*"Will the APA Listen to the Voices of Those Harmed by Psychiatric Diagnosis?"* Mad in America, 2012

The *DSM* evolved from several needs to:

· Create a system of monetary compensation.

· Distinguish the profession of psychiatry from other helping professions, making it more "scientific" and authoritative.

· Create research criteria.

The companion book to the *DSM* is called the **International Classification of Diseases (ICD-9)**, which assigns a six-character alphanumeric code to every disease. Without a billing code the government or private insurance provider won't pick up the tab.

For this reason, some people refer to the *DSM* as the "Billing Bible."

The problems related to the *DSM* are too numerous to outline and describe for purposes of this organizing handbook, but consider two of the most common criticisms:

First, credible experts have argued the reliability of the *DSM* is a "myth" and that rhetoric, not science, characterizes the *DSM*.

Download *"The myth of reliability of DSM"* (PDF) from: **mindfreedom.org/myth-reliability-dsm**

Second, the adoption of disease classifications in the *DSM* has not led to any innovations in the care and treatment of "mental illness" for nearly fifty years. In fact, researchers are pulling away from using the *DSM* because of its lack of scientific validity.

NUT

Just two weeks before **DSM-5** was due to appear, the National Institute of Mental Health (NIMH), mindfreedom.org/health-psychology-today, the world's largest funding agency for research into mental health, indicated that it was withdrawing support for the manual.

In a humiliating blow to the American Psychiatric Association, mindfreedom.org/psychiatry-psychology-today, Thomas R. Insel, MD, director of the NIMH, made clear the agency would no longer fund research projects that rely exclusively on **DSM** criteria. The NIMH, which had thrown its weight and funding behind earlier editions of the manual, would be "reorienting its research away from **DSM** categories." "The weakness" of the manual, Insel explained, "is its lack of validity." "Unlike our definitions of ischemic heart disease, lymphoma, or AIDS, the **DSM** diagnoses are based on a consensus about clusters of clinical symptoms, not any objective laboratory measure."

View a commentary describing what this means for the future of the **DSM**: mindfreedom.org/nimh-withdraws-support-dsm5

Robert Whitaker, award-winning journalist and author of **Anatomy of an Epidemic**, summed up why challenging the **DSM**'s validity is important:

> "I think this challenging of the validity of **DSM** is, in many ways, potentially much more of a paradigm changer than are the scientific reports that detail how the medications may be causing long-term harm. Our current drug-based paradigm of care, which presents drugs as treatments for the symptoms of a 'disease' stems from **DSM III.** The APA and its leaders boasted that when **DSM III** was published in 1980, that the field had now adopted a 'medical model'

Robert Whitaker, author

> and that now its manual was 'scientific' in kind.

In fact, the APA had adopted a 'disease model,' and if you carefully read the **DSM III** manual, you saw that the authors acknowledged that very few of the diagnoses had been 'validated.' The APA's hope and expectation was that future research would validate the disorders, but that hasn't happened. Researchers haven't identified a characteristic pathology for the major mental disorders; no specific genes for the disorders have been found; and there isn't evidence that neatly separates one disorder from the next. The 'disease model,' as a basis for making psychiatric diagnoses, has failed." —Interview by Bruce Levine, TruthOut, March 5, 2014

NUT

The Harm of Receiving a Diagnosis

Many experts claim that a psychiatric diagnosis itself harms people. Paula Caplan, a psychologist and former contributor to the **DSM**, came to this conclusion after working for years with clients who had been harmed by diagnostic labels. She describes the nature of this harm in the article *"Psychiatry's Bible, the DSM, is Doing More Harm Than Good:"* **mindfreedom.org/dsm-bible-harm**

Dr. Peter Breggin, a medical researcher who also maintains a private practice in psychiatry, is also highly critical of the **DSM**:

"Psychiatric diagnoses are always negative. There are no such diagnoses as 'Exceptionally Able to Face Stress' or 'Remarkably Resilient' or 'Courageously Independent in the Face of Abuse.' That's how I like to think about the people that I try to help—as heroes or potential heroes in their own life stories. I never want them to sum up, categorize or symbolize their lives in such a demeaning fashion as a psychiatric diagnosis.

But that's only the beginning of the problem. These diagnoses imply that you or your children have a disease, especially an underlying biochemical imbalance. This can be discouraging and disempowering. Having a psychiatric diagnosis tends to make us feel helpless to transform our lives or the lives of our

children for the better. It makes us feel less responsible for our own psychological and spiritual recovery and for that of our young and dependent children."—Peter Breggin*, "The Hazards of a Psychiatric Diagnosis"* **mindfreedom.org/hazards-psychiatric-diagnosis**

Perhaps the most compelling critics of the **DSM** are "experts by experience"—the very people who received a **DSM** label and were told that they would never recover.

As a part of its I Got Better campaign in 2012, MindFreedom International (MFI) encouraged people to come out of the closet regarding their past psychiatric diagnoses. Hundreds responded and shared their experiences being diagnosed and treated in the mental health system.

80 percent answered yes to the question, "During your mental health care, have you often felt hopeless about your chance of getting better?" When asked about the source of their hopelessness, *75 percent of respondents indicated that the* Source *of their hopelessness came from medical professionals.* Source: **igotbetter.org**

In the 1970s, psychiatric survivors began pushing back on the credibility of the **DSM** based on their experience being told they had a permanent brain disease.

Today, many medical scientists are joining psychiatric survivors by saying it is time to lay the **DSM** to rest. Critics point out that identifying mental health disorders has been permanently tainted by politics and is not the least bit scientific or helpful.

Other critics are satisfied to remove specific diagnostic labels that have outlived their usefulness, such as schizophrenia. The eminent psychiatrist Sir Robin Murray describes how:

> "The concept of schizophrenia is dying. Harried for decades by psychology, it now appears to have been fatally wounded by psychiatry, the very profession that once sustained it. Its passing will not be mourned . . .

"I expect to see the end of the concept of schizophrenia soon . . . the syndrome is already beginning to breakdown . . . the term schizophrenia will be confined to history, like 'dropsy'." mindfreedom.org/schizophrenia-concept-end

MindFreedom International and other activists called for a boycott of the **DSM**: mindfreedom.org/boycott-dsm-mindfreedom

MFI was not alone. In 2012, more than 20,000 professional allies, including counselors, psychologists, dissident psychiatrists, social workers, and nurses, signed a petition calling for a boycott of the **DSM-5**.

The People's **DSM** was launched by an MFI affiliate in Portland, Oregon, allowing psychiatric survivors a chance to enjoy some well-needed levity while conceiving their own mental health labels. Of course, the People's **DSM** is lacking in scientific merit, but activists argue so does the **DSM-5**! The People's **DSM** is: mindfreedom.org/peoples-dsm-wiki

Allies in the helping professions believe that the only way to permanently banish the **DSM** is to create another framework by which to support people in distress. Creating more effective and humane mental health services begs the question, who will pay for these services? Some mental health professionals suggest that we replace the **DSM** with the *Power Threat Meaning Framework* of supporting people with mental and emotional challenges.

NUT

Power Threat Meaning Framework of Diagnosis

The *Power Threat Meaning Framework* was published in 2018 by the British Psychological Society's Division of Clinical Psychology. The purpose is to identify "patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis."

This model recognizes that treating power imbalances in society is far more effective than treating unproven chemical imbalances. Read the entire description at:
mindfreedom.org/power-threat-meaning-framework

If adopted, this would give treatment providers an alternative way to support clients in distress and bill insurance for services. It would allow people who seek professional services to avoid psychiatric labels that later become a part of their permanent medical records.

mindfreedom.org/power-threat-framework-perspective

mindfreedom.org/power-threat-framework-challenges-tradition

Psychological Formulation

Psychological formulation is a rapidly expanding practice in the United Kingdom that is supported by the British Psychological Society. It is argued that formulation can provide a credible alternative to psychiatric diagnosis in the context of public admissions about lack of reliability and validity of current diagnostic systems. Read a summary of psychological formulation at: mindfreedom.org/psychological-formulation

mindfreedom.org/psychological-formulation-alternative-diagnosis

Items for Action

Read from experts on how politics and greed have tainted the *DSM*:

- · ***The Book of Woe: The DSM and the Unmaking of Psychiatry*** by Gary Greenberg
- · ***Unhinged: The Trouble with Psychiatry—A Doctor's Revelations about a Profession in Crisis*** by Daniel Carlat, MD

Read Jack Carney's challenge to other social workers to join the fifty-one other professional organizations to boycott the ***DSM-5***: mindfreedom.org/dsm5-boycott-carney

Sign one of the many petitions circulating on the Internet to boycott the *DSM*.
mindfreedom.org/campaign-boycott-dsm
mindfreedom.org/boycott-petition-dsm-change.org
mindfreedom.org/petition-boycott5

Create your own label!
The People's ***DSM*** allows psychiatric survivors a chance to enjoy some well-needed levity and take back the power to name what ails you! As with the ***DSM-5***, the labels found here have not been scientifically "field tested" but they have far less power to harm.
mindfreedom.org/peoples-dsm-wiki

Join an activist discussion group.
mindfreedom.org/facebook-drop-the-disorder-discussion-group

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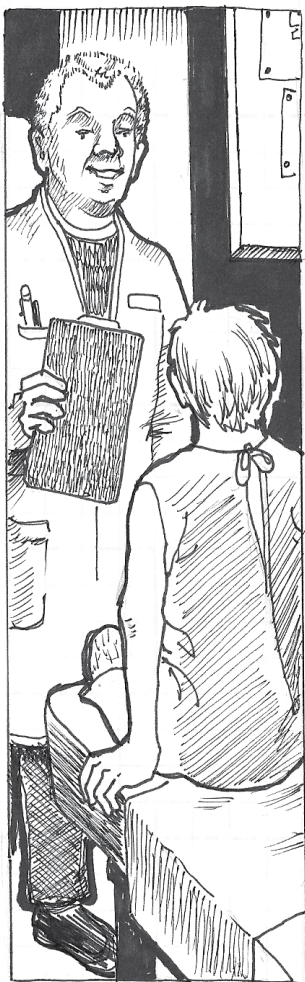
After a Diagnosis

People react in different ways after receiving a mental health diagnosis. For some, a diagnosis may provide relief. It may also offer pathways to receiving important social services such as housing, or income support.

On the other hand, many experience fear, anger, or hopelessness. It is natural for people to be skeptical about or reject a diagnosis, especially if the person making the diagnosis acts like a know-it-all, has not established trust with you, and exhibits few likeable qualities.

Diagnosis Shopping

It is common for people to seek to have their diagnosis "downgraded" to one that is less stigmatizing. Some activists argue that diagnosis "shopping" reinforces, rather than calls into question, the scientific validity of the *DSM* and psychiatry in general. "Why should I subject myself to a process that lacks scientific validity?" some survivors ask.

A mental health diagnosis, especially one considered more "severe" such as bipolar or schizophrenia, may result in loss of personal agency or civil liberties.

Sometimes individuals contact MFI because they are seeking an expert to help them dispute a mental health diagnosis. They think this will result in better treatment or a restoration of their civil liberties.

Unfortunately, the reality is that it is nearly impossible to convince a psychiatrist to "reverse" a diagnosis. As a result, many mental health advocacy organizations advise people to simply learn how to live better with their diagnosis.

Mental Health of America, a mental health consumer advocacy organization, advises individuals who receive a diagnosis to "be hopeful and learn all you can about your diagnosis."

Even if one believes that the *DSM* is scientifically credible, here are some of the many challenges involved in getting unbiased information about one's diagnosis from readily available sources (websites, blogs, mainstream media, etc.):

· The most popular Internet sites having to do with medical information are rife with conflicts of interest. WebMD and its sister site MedScape are the top recipients of industry dollars (pharmaceutical, biotech, medical devices, hospitals, health insurance companies, etc.) See others: **mindfreedom.org/truth-about-webmd**

· Most sites fail to present information critically, as if drugs are the only "real" treatment option for mental and emotional distress.

· Most sites exclusively promote the disease model without providing any long-term data about the effectiveness of treatment under this model. Scientific data showing that psychosocial treatments without drugs result in superior long-term outcomes is rarely, if ever, presented on mainstream sites.

· When alternatives such as the psychosocial model are mentioned it is usually only in a passing manner, as if these approaches exist only to compliment the primary treatment model (drugs).

· Personal testimonies from individuals who experienced meaningful and lasting recoveries from even the most extreme states without the use of drugs are rarely presented.

Other problems with industry-funded, mainstream information sources include:

· Some individuals receive a mental health diagnosis based on iatrogenic (doctor caused) behavior. Yet websites funded by drug companies and the media rarely, if ever, present this information to consumers.

NUT

- Many individuals receive a diagnosis based on trauma-induced behavior, yet very few mental health professionals are trauma informed. The role of Adverse Childhood Experiences (ACEs), trauma, or abuse, including psychiatric abuse, is rarely, if ever, mentioned.
- We are culturally trained to trust medical doctors. Once a diagnosis is received, we often leave our critical thinking at the door and leave decisions up to the so-called experts.

Trauma Routinely Dismissed

Dr. Paula Caplan claims that a psychiatric diagnosis often comes on the heels of trauma. She points out that people receiving harmful or dehumanizing mental health treatment are often retraumatized.

> "Looking back, I realize that I was heartbroken because I was in this horrible living situation and not getting any support or validation for how I was feeling. Instead of dealing with that, they shocked my mind. This treatment was completely and totally irrelevant to what was going on for me. What I was going through was an emotional thing and not a mental thing."
> —Barb Green, psychiatric survivor

Very few psychiatrists are trauma informed. They rarely, if ever, receive training in psychotherapy, which emphasizes listening, and they are unlikely to take the time to understand a person's history in the process of making a diagnosis.

Psychiatric Malpractice

After receiving harmful treatment following a questionable diagnosis, many ask if they can sue their psychiatrist. Malpractice cases involving psychiatry are difficult to win because of stigma and discrimination ("Who will take the word of a crazy person?"). Psychiatric malpractice awards are typically lower than other forms of medical malpractice. Expert witnesses are very expensive, and attorneys rarely accept such cases. More information on psychiatric malpractice cases can be found at: mindfreedom.org/psychiatric-malpractice-article

A first step in filing an effective malpractice case is to obtain one's medical records and a secondary mental health evaluation that contradicts the first one.

Individuals who want to pursue this strategy should locate a mental health professional who is either openly critical of the current diagnostic or "disease" model or will respect your right to choose your own pathway to wellness. Below are some resources to help you locate alternative practitioners.

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How to Find an Alternative Practitioner

Alternative Directories
Finding a medical professional who supports your right to choose alternative and integrative pathways to wellness can be very challenging! Some nonprofit organizations maintain directories on their websites to help people find a provider who will respect their values and treatment preferences.

MindFreedom International
MFI vets providers on the basis of their willingness to honor nondrug/nonforce options: mindfreedom.org/directory/gateway-d1

Safe Harbor
Safe Harbor lists medical providers who tend to employ holistic or integrated approaches:
mindfreedom.org/safeharbor-provider-directory

Foundation for Excellence in Mental Health Care
FEMHC vets providers who share the organization's desire to change the paradigm of mental health care:
mindfreedom.org/foundations-mental-health-providers

How to Obtain Medical Records

Here is a source to help individuals obtain their medical records:
mindfreedom.org/hipaa-maintain-records

How to File Complaints against a Psychiatrist

Here is a source on how to file a complaint against a psychiatrist:
mindfreedom.org/psych-search-complaint-filing

Questions to Ask Yourself About Your Diagnosis

Whether you decide to question your diagnosis or accept it as valid or useful is a personal decision. In making your decision, it may help to ask some questions about the circumstances leading up to your diagnosis:

1. Did you receive a diagnosis on the heels of unfavorable circumstances such as a recent job loss, a divorce, etc.?

2. How much support did you receive to help you deal with problems in your life in the days/months/years leading up to your diagnosis?

3. Were you forced or court ordered to receive a mental health evaluation or treatment by a judge in a civil or criminal hearing? If so, did you receive good legal counsel?

4. As a child or adult, were you pressured by family members to accept a mental health evaluation? If so, were there extreme power imbalances in your family?

5. Was the methodology of the evaluation explained to you in a way that you could understand?

6. Did the person making the diagnosis discuss any negative ramifications of receiving a diagnosis? (These negative ramifications are well-documented.)

7. Did you vocalize any concerns or resistance in relation to your diagnosis? If so, how did the person making the diagnosis react?

8. Do you feel the person diagnosing you lacked understanding of where you are coming from based on your race, ethnicity, gender, socio-economic situation, sexual orientation, etc.?

9. While you were being evaluated, was your behavior altered by something traumatic that happened to you in the past? If so, do you think the evaluator took the time to understand your personal history and the context of your behavior and emotions?

10. Were you too afraid or ashamed to talk about things that happened to you?

11. While being evaluated, was your behavior or cognition influenced by drugs (prescribed or recreational)?

12. In the days leading up to your evaluation, were you in a locked facility, subject to solitary confinement or forced drugging?

13. Was information about your previous behavior shared from other third-party observers without your permission?

14. Was information about you taken out of context?

15. Were family members present during your evaluation? Were they truthful? Did you trust them?

16. Did family members exaggerate things that you said or did?

17. Do you suspect that you experienced an adverse drug reaction to one or more psychiatric drugs that you were taking, either voluntarily or by force, in the days or weeks leading up to your diagnosis?

18. Were you experiencing withdrawal symptoms when attempting to discontinue psychiatric drugs that you found unhelpful or harmful?

19. Is the person who evaluated/diagnosed you under pressure to diagnose and treat people as quickly as possible for reimbursement purposes?

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Items for Action

1. Obtain your medical records:
    mindfreedom.org/hipaa-maintain-records

2. Search for an alternative provider in your community:
    mindfreedom.org/directory/gateway-d1

3. Search for a peer support group in your community. If one
    does not exist, consider starting a MindFreedom affiliate
    in your community. Directions for starting an affiliate can
    be found here: **mindfreedom.org/affiliates-sponsors**

4. Refer to Tree section of this handbook to learn about non
    force/nondrug alternative pathways to mental wellness
    through peer support and other community based models.

Notes:

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Medical Model

"There is now unequivocal evidence of the failures of a system that relies too heavily on the biomedical model of mental health services, including the front-line and excessive use of psychotropic medicines, and yet these models persist . . . This pattern occurs in countries across the national income spectrum. It represents a failure to integrate evidence and the voices of those most affected into policy, and a failure to respect, protect, and fulfill the right to health."

—"United Nations Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health"

mindfreedom.org/rapporteur

Biological (Disease Model)

Psychiatric survivors and their allies often criticize the "medical model," sometimes referred to as the "biomedical" or "disease" model. It refers to the brain chemical imbalance argument or "monoamine hypothesis" used by many psychiatrists to rationalize one-size-fits-all treatment that many survivors find harmful and dehumanizing.

Some physicians such as Harriet Cooke, MD, believe it is important not to paint all medical practitioners with the same brush:

> "A biological model ideally looks at mental health from an integrative perspective and to identify the origins of behavior as that may be the result of biological processes of the body. There is consensus for many of these influences. Endocrine disorders are well known to produce depression and nutritional deficiencies can produce behavior that is often attributed to 'schizophrenia.' Heavy metal and other

toxicity, the health of the gut, infections, food sensitivities—including gluten intolerance, tumors, autoimmune disorders, and metabolic disorders—all can affect our mental health profoundly."

The practice of psychiatry has been based for about seventy years on an unproven model that mental health is maintained when chemicals known as neurotransmitters are in proper balance.

Dr. Cooke believes that although the medical model has prioritized pharmaceutical management in the "treatment" of mental health challenges, chemicals can often play an important role.

> "Chemicals, whether pharmaceutical, recreational, natural supplements, fermented food (alcohol), or other 'foods' such as coffee, also affect our mental and emotional state and behavior. What is medicine for one individual at one dose, at one time, is toxic for another."—Dr. Harriet Cooke

Medical Model as it is Really Practiced Today

"Despite the fact that no known brain chemical imbalances have ever been confirmed by replicable proof, the American Psychiatric Association states on its website that 'abnormalities in two chemicals in the brain, serotonin and norepinephrine, might contribute to symptoms of depression' and later on that 'antidepressants may be prescribed to correct imbalances in the levels of chemicals in the brain."—Dr. Joanna Moncrieff. Source: mindfreedom.org/joanna-moncrieff-depression-theory

Ronald Pies, MD, clinical professor of Psychiatry at Tufts University, and former editor of Psychiatric Times, recently stated, "The 'chemical imbalance' notion was always a kind of urban legend–never a theory seriously propounded by well-informed psychiatrists."

This was an astonishing admission. Dr. Pies and other leaders within organized psychiatry attempted to publicly backpedal from this statement. Psychologist Philip Hickey summarized the many ways that organized psychiatry has consistently promoted

this unfounded theory of chemical imbalances involving neurotransmitters for years, making it a difficult position to disavow. See more: mindfreedom.org/psych-promotion-imbalance

At worst, promotion of the chemical imbalance theory by organized psychiatry is viewed by critics as deliberate fraud. At best, psychiatric leaders and academics seem disconnected from the clinical practices that take place on a daily level.

Tens of thousands of individuals, when treated by force or coercion with harmful psychotropic drugs, continue to be told "you have a chemical imbalance and you have to take these medications for life." Source: igotbetter.org

Since the integrative medicine practices described by Dr. Cooke are the exception and not the norm, some activists support alternative integrative biological treatment options such as nutritional approaches, as long as they are voluntary and "first do no harm."

The Language of "Mental Illness"

The language people in most Western industrialized societies use, such as the term "mental illness," clearly illustrates the domination of the medical model.

Some leaders call for the elimination of clinical language to describe the experiences of psychiatric survivors:

> "Let's . . . drop the use of other words that tend to confine us in the dominant model. Let's stop legitimating the use of words and phrases like 'patient' and 'chemical imbalance' and 'biologically-based' and 'symptom' and 'brain disease' and 'relapse' and all the rest of the medical terminology when we are speaking about those of us who have been labeled with a psychiatric disability.
>
> My call is not about opposing the medical model, or any other particular model. My call is about opposing domination by any model in this complex field. My call is about opposing bullying in mental health care."—David Oaks, Psychiatric survivor/

NUT

Most mental health services are based on the assumption that mental health disorders are chronic diseases of the brain. While there is no consensus on the "monoamine hypothesis," and there are many different causes for the same mental-emotional symptoms—the overuse of this theory has been extremely profitable to the pharmaceutical industry. This profit motive directs research into this line of reasoning and away from more comprehensive understanding that would lead to an integrative model with far fewer pharmaceuticals being used for mental health issues.

In science, a model is a representation of an idea, an object, or even a process or a system that is used to describe and explain phenomena that cannot be experienced directly. Models are central to what scientists do, both in their research as well as when communicating their explanations.
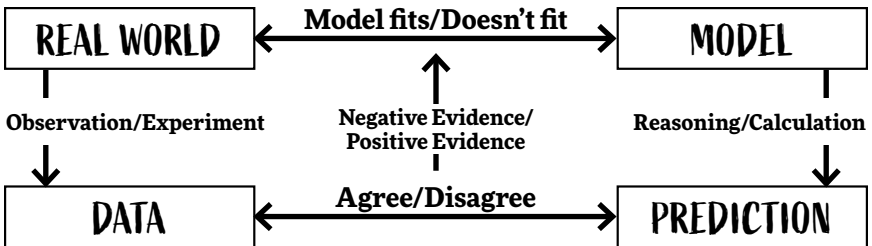
Bloodletting is an example of a medical practice that was based on a faulty model, an ancient system of medicine in which blood and other bodily fluids were regarded as "humours" that had to remain in proper balance to maintain health.

Similarly, the practice of psychiatry is based on an unproven model that mental health is maintained when chemicals known as neurotransmitters are in proper balance. This model is under fire due to lack of consensus in scientific evidence.

A Summary of Models

Psychologist Gregg Henriques describes "Five Broad Models of Mental Illnesses" in Psychology Today. Read the full article at: **mindfreedom.org/five-broad-models-mental-illness**

The Models are:

· Biological and neurophysiological (Disease Model)
· Spiritual Model
· Moral Model
· Sociological Model
· Learning and developmental (Psychological Model)

Disease Model

Individuals who voluntarily seek support from the mental health system today often must be willing to receive services that are based on the biological or disease model. This means accepting a diagnosis from the DSM for which the preferred treatment will be psychiatric drugs—with or without counseling therapy, possible confinement, and electroconvulsive shock.

Spiritual Model

When the topic of spirituality is raised in relation to mental health most people think of The Exorcist. In reality, most spiritual approaches are far more different than what Hollywood would have us believe.

Many spiritual traditions view madness as a potentially meaningful process leading to greater wisdom and personal insight. For example, in some indigenous cultures, special status is conferred to individuals who experience altered states of consciousness.
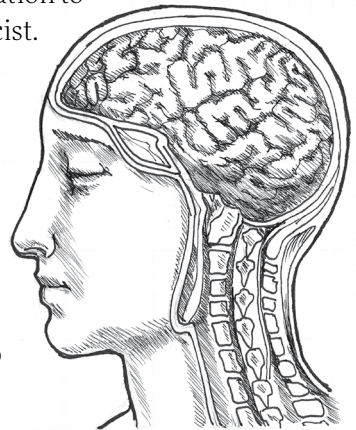
Indigenous cultures also recognize mental "illness," and understand the need to wait—often a period of months

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or even years—for transformational experiences to settle into a more expansive state that can greatly benefit the community.

Support is often channeled, interpreted, and guided by the services of a spiritual guide, mentor, or shaman. This approach is profoundly different from Western cultures in which the experience of madness is medicalized and suppressed, leading to isolation and confinement.

The documentary Crazywise by filmmaker Phil Borges compares how different cultures perceive altered states of consciousness. What is considered "mental illness" in Western industrialized societies may be considered a positive transformative experience in other cultures. View the trailer at: crazywisefilm.com

Dr. Malidoma Patrice Somé, a native of Burkina Faso, West Africa, initiated into the ancestral traditions of his African Dagara tribe, wrote about his experience of visiting a modern mental hospital in the US. Read an article describing that visit: mindfreedom.org/what-shaman-sees-mental-hospital

In the book **Spiritual Emergency** (1989), Psychiatrist Stanislav Grof and his wife, Christina Grof, bring together essays from western psychiatrists and psychologists who focused their work in the realm of spiritual emergence.

In his video, Am I Bipolar or Am I Waking Up, Sean Blackwell, founder of Bipolar Awakenings, documents his own emergence from a state of consciousness labeled "psychosis" into a greater awareness and sense of purpose in life. You can view the first of the five-video series: mindfreedom.org/am-i-bipolar-video. Learn more about Sean on his blog: bipolarawakenings.com

In her essay *"Spirituality and Mental Illness,"* Kelly Brogan, MD, describes her personal and professional evolution away from treating patients who have mental and emotional challenges, primarily by suppressing symptoms of distress with drugs, to a holistic recovery approach integrating elements of spirituality. Her entire essay can be read here: **mindfreedom.org/kelly-brogan-spirituality-mental-illness**

> **"Is the suppression of spirituality in the West the reason for our struggle and suffering labeled as mental illness? Are we medicated to numb the pain and psychospiritual protest related to the felt wrongness in our modern lives? Here's what I learned from my trip to India . . ."**
>
> *–Dr. Kelly Brogan*

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Another relevant article is *"Dark night—healing the shadow and the dark emotions,"* by Monica Cassani. To read the full article, visit: **mindfreedom. org/beyond-meds-healing-the-shadow**

In a group discussion on the Facebook page "The Shamanic View of Mental Illness," (**facebook.com/groups/the.shamanic.view.of.mental. illness**) Todric Kam Koenig states:

> "Any 'spiritual model' will vary from culture to culture; you probably are not going to find a one-size-fits-all traditional spiritual perspective."

Jartsa Tartsan, in the same discussion, points out that consciousness is seen differently by shamans in most cultures:

> "There's no such thing as supernatural. Everything that exists is by definition, natural. There also is no single model that could define all mental illness. It depends on the situation and culture and various other things, but if you're looking for a definition of consciousness, you could say that the modern materialistic view considers consciousness to be an emergent property of

brain function, whereas shamanic tradition considers it the other way around: the material world is an emergent property of consciousness. Funny enough, quantum mechanics seems to prove this (shamanic) viewpoint: observation affects quantum phenomena, and observation requires consciousness . . . from this we can deduce that reality is created by conscious observation."

Moral Model

Gregg Henriques, PhD, states, "In a nutshell, the position of moral character is that there are virtues which one must learn, such as courage and fortitude, honesty, and integrity, compassion and grace that enable one to live the admirable life."
mindfreedom.org/five-broad-models-mental-illness

Credit: Wikimedia Commons

During Europe's "Bedlam" era starting in 1750, mental patients were "bled," spun in chairs, and held underwater until they lost consciousness. The Moral Model came into existence partly in response to this extraordinarily cruel treatment.

"'Moral treatment' emphasized treating people with kindness and empathy, and avoiding medical remedies that 'worked' by weakening the patient. Moral treatment emphasized that mental patients should be seen as part of the human family." Read the full article at:
mindfreedom.org/mad-america-chapters

This form of care initially produced good outcomes but gradually fell out of favor. In "Mad in America," Robert Whitaker speculates that asylums employing the Moral Model diluted their mission by accepting all of society's "undesirables," including people who dealt with syphilis, alcoholism, etc. as a result of the asylums' overcrowded state. Consequently, this model could no longer sustain the conditions necessary for continued success.

Psychological Model

Henriques states, "The general model here (from Freud to Rogers to Skinner to Beck) is that the individual develops along a trajectory and attempts to adapt to their environment. However, if the individual fails to learn certain crucial elements or learns the wrong responses to new situations or adopts short term solutions that have long term maladaptive consequences, then suffering and dysfunction result." Source: **mindfreedom.org/five-broad-models-mental-illness**

Al Galves, PhD, a psychologist and author of ***Harness Your Dark Side: Mastering Jealousy, Rage, Frustration and Other Negative Emotions,*** dedicated his career to using the development/psychological model in order to help people understand how the states of being and behaviors that are associated with diagnoses of "mental illnesses" are related to their life situations and to concerns about their lives and themselves. Emotional distress, life crises, difficult dilemmas, and spiritual emergencies can overwhelm. Mental illnesses are essentially how people avoid emotional pain, protect themselves, and gain the illusion of control in a world in which the most dangerous things are outside of our control.

HARNESS YOUR DARK SIDE

Mastering Jealousy, Rage, Frustration and Other Negative Emotions

AL GALVES, Ph.D.

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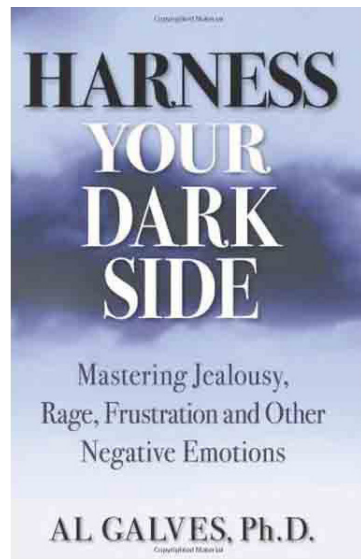
In his work and teachings, he emphasizes that mental illnesses are reactions to significant loss as well as wake-up calls—signals that something is wrong and needs to be dealt with. He teaches that mental illnesses are reactions to difficult, scary, terrifying, rage-creating life situations. He suggests that people who have been labeled with a "mental illness" are dealing with universal concerns such as:

· Am I going to be able to live the way I want to?

· Am I going to be able to connect with other people in satisfying ways?

· Will I be able to build a love relationship that will enable me to have a satisfying love life and family life?

· Am I going to be able to find a job that is satisfying and which pays enough to support me?

· Am I smart, strong, personable, attractive, creative, resilient, flexible enough to be able to live the way I want to live?

· Am I adequate or inadequate?

· Am I going to be able to do what I want to do or am I going to have to shrink myself to fit into the only roles, jobs, relationships that are available to me?

· Am I OK the way I am?

· Am I worthy of living?

In order to be mentally and emotionally healthy, human beings have to be able to love the way they want to love and express themselves the way they want to express themselves. They have to be connected to other people in satisfying ways, experiencing all kinds of love—romantic, sexual, familial, collegial, friendship. They have to be able to use their abilities and faculties in satisfying and productive ways, be able to investigate the world, and engage in expressive activities such as building things, creating art, singing, dancing, playing sports, helping other people, etc. If they can't do that, they become agitated, angry, debilitated, weak, anxious, obsessive, panicked. They may exhibit behavior that gets labeled as "manic," and "psychotic," or "mentally ill."

One of the great benefits of understanding mental illness this way is that it leads people to seek treatment that will help them learn how to live more satisfying lives, how to use their thoughts, emotions, intentions, perceptions, reactions, and behavior in life-enhancing ways. That, unlike their brain chemistry and genetic dynamics, is something they have control over. More from Al Galves, visit: **mindfreedom.org/al-galves**

Sociological

According to Henriques, "Here the focus is on the macro structures of power and resources, the social construction of what constitutes illness and which individuals are socially sanctioned to declare who is mentally ill, labeling and the manner in which mental illnesses are distributed and treated in different cultures. At the extreme, the sociological level disavows the entire concept of mental illness. The psychiatrist Thomas Szasz famously argued that "mental health professionals are secular priests and that mental illness was simply labels for deviant individuals that society deemed needed to be controlled." For the full article, visit: **mindfreedom.org/five-broad-models-mental-illness.** For more information about the life and work of Thomas Szasz visit: **mindfreedom.org/thomas-szasz**

Medical Model, Stigma, and Disempowerment

Researchers have found that stigma is actually worsened by biological disease explanations for mental health disorders despite decades of "anti-stigma" campaigns funded by drug companies.

A meta analysis of studies measuring public perception of people labeled with "mental illness" found that biological (genetic) explanations increased public rejection of people with mental illness while psychosocial explanations increased acceptance: **mindfreedom.org/biogenetic-explanations-systemic-review**

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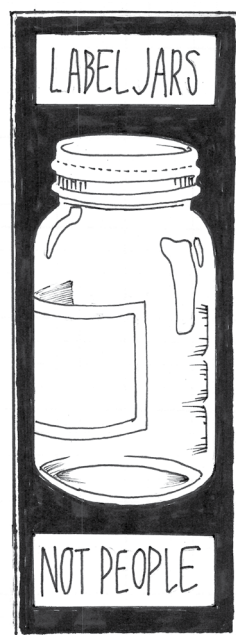
Stigma associated with diagnostic labeling is not limited to the family members and the general public. Treatment providers also stigmatize clients with particular labels, resulting in overall lower quality of medical care. Read the study at: **mindfreedom.org/role-labeling-stigmatization**
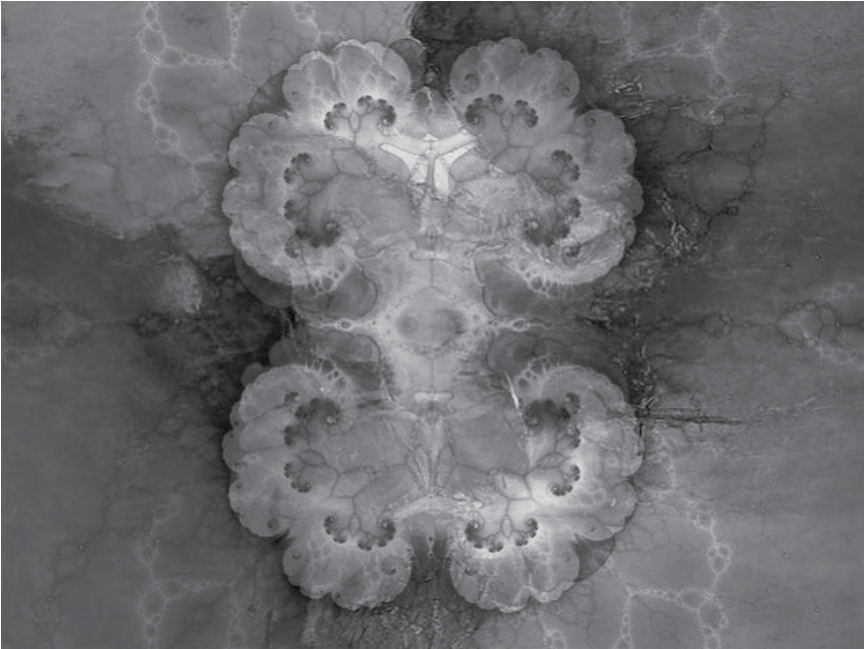
Old World Brain, by Tom McNamee

"Could there be a more disempowering message than to tell a young person that there is something permanently wrong with his or her brain? And if there is something wrong with a student's brain, why should he or she work hard to master difficult concepts and skills?"

–David Mielke

mindfreedom.org/adhd-disempowerment

This is how David Mielke, MS, describes the "learned helplessness" and disempowerment that go hand in hand with labels like ADHD. Although the focus of the article is ADHD involving young people, the issues he raises can easily be applied to other mental health labels.

> "Diagnoses imply that you or your children have a disease, especially an underlying biochemical imbalance. This can be discouraging and disempowering. Having a psychiatric diagnosis tends to make us feel helpless to transform our lives or the lives of our children for the better. It makes us feel less responsible for our own psychological and spiritual recovery and for that of our young and dependent children."—Peter Breggin, *"Hazards of Psychiatric Diagnosis"* HuffPost, June, 2011: mindfreedom.org/hazards-psychiatric-diagnosis

In an effort to encourage more people to seek mental health treatment, a great deal of "anti-stigma" campaigns have been launched by mental health advocacy organizations, many of which are funded by drug companies. This meta-analysis shows that viewing "mental illness" as a biologically based disease may, in fact, increase stigma. Read more at: mindfreedom.org/do-biological-explanations-reduce-stigma

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Brett Deacon, PhD, and James Lickel, MS, explain the relationship between the medical model and stigma in the article *"On the Brain Disease Model of Mental Disorders"* in The Behavior Therapist:

> "For years, proponents of the 'brain disease' model of mental illness have argued that if we see depression and other mental disorders as real, physical diseases, people who have them will no longer be stigmatized as they were in the past. The idea is that if the problem is truly biological, it cannot be seen as a flaw in the character or will power of the person who suffers.

> It's a nice piece of reasoning. The problem is not only that it is not scientifically proven that depression, anxiety, and their ilk are biological diseases, but also that defining them in that way is as likely to create stigma as it is to destroy it."

> "Biological models foster the perception that individuals with mental disorders lack control over their behavior, they may be viewed by others as unpredictable, dangerous, unable to care for themselves, requiring harsher treatment, and fundamentally different from those without mental disorders.

> In fact, there's a whole literature of studies that find that biological explanations of mental disorder are associated with greater fear of and prejudice toward people who are in mental distress." Read the full article at: mindfreedom.org/brain-disease-model-bad-medicine
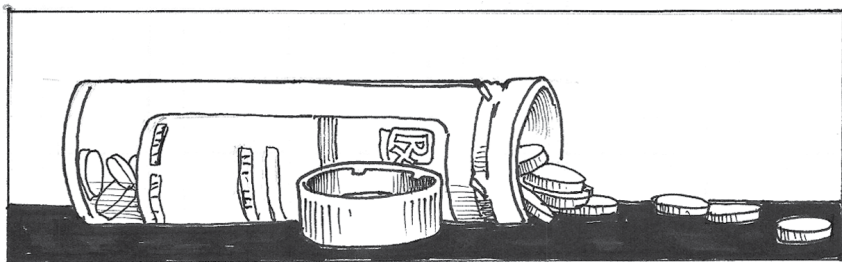
Medical Model and Human Rights Abuses

For thirty years, MFI has taken the position that people should have choices, including the choice to not view themselves as having a disease as defined by the DSM. Currently, people who reject their own mental health diagnoses are often given the label of anosognosia, a subjective term that is not supported with vigorous scientific evidence.

In her article, "Anosognosia: How Conjecture Becomes Medical 'Fact'," Dr. Sandra Steingard, a psychiatrist, claims the term anosognosia "confers a certain sophistication of understanding and knowledge that is not supported by the data." Read the full article at: **mindfreedom.org/anosognosia-conjecture**

If people believe that their diagnosis and psychiatric drugs are helpful, MFI takes the position that it is their right to have that belief. But MFI also maintains that society does not have a right to impose by force or coercion any psychiatric intervention on individuals without their expressed consent.

MFI believes that the domination of the disease model to the exclusion of other models, as well as the use of force and coercion to administer harmful "treatment," has resulted in a tsunami of physical, emotional, and psychological harm to individuals.

The unavailability of choices and alternatives in the mental health system is due to a gradual shift in how our culture perceives individuals who exhibit socially undesirable behaviors. These perceptions have been molded for years by drug companies that now spend more on marketing than on research. Source: **mindfreedom.org/pharma-spending-marketing**

The adoption of the medical model at the exclusion of all other models has serious consequences for those who receive mental health diagnoses and psychiatric interventions, especially those who receive treatment by force or coercion. Lack of choices or alternatives in the mental health system is, therefore, a human rights issue.

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On March 4, 2013, in a statement to a session of the United Nations Human Rights Council in Geneva, the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment of Punishment called for a ban on forced psychiatric interventions including forced drugging, shock, psychosurgery, restraint, and seclusion, and for repeal of laws that allow compulsory mental health treatment and deprivation of liberty based on disability, including when it is motivated by "protection of the person or others." Read more online at: **mindfreedom.org/un-rapporteur-forced-treatment** and read the full treaty at: **mindfreedom. org/un-convention-disabilities**

Treating Chemical "Imbalances" Does not Improve Outcomes

The serotonin imbalance theory of depression has already been dismissed by prominent scientists as having zero evidence. Still, this hasn't prevented advertisers or stopped many prescribers from telling their patients that "antidepressants" correct a chemical "imbalance." Likewise, neuroleptics, commonly known as "antipsychotics," do not correct any known mechanism of "psychosis." At best, they suppress symptoms while creating new unintended side effects. Furthermore, a meta-analysis confirms that the statistical difference between antidepressants and placebo is not clinically relevant. Source: **mindfreedom.org/ empirically-derived-criteria-antidepressant**

Many critiques of the medical model point out that people in extreme emotional distress who receive nondrug alternatives have been shown to enjoy superior long-term outcomes. (See the Tree section of this handbook for more details.)

The perception that "antidepressants" are working on the origin of a problem is firmly embedded in the general public perception, and molded by billions of advertising. The majority of the effect of antidepressants can be attributed to placebo. Source: **mindfreedom.org/kelly-brogan-placebo-effect**

In this article, *"Serotonin and Depression: A Disconnect between the Advertisements and the Scientific Literature,"* the Psychiatrist David Healy

states, "In the 1990s, no academic could sell a message about lowered serotonin. There was no correlation between serotonin reuptake inhibiting potency and antidepressant efficacy. No one knew if SSRIs raised or lowered serotonin levels; they still don't know. There was no evidence that treatment corrected anything." Source: **mindfreedom.org/serotonin-depression-myth**

Further, Jeffrey R. Lacasse and Jonathan Leo argue that the same lack of evidence for the chemical imbalance theory of depression can also be applied to other mental health disorders such as ADHD. Read the entire argument at: **mindfreedom.org/ challenging-narrative-chemical-imbalance**

Dr. Peter Breggin, often called the "conscience of psychiatry," discusses the myth of the chemical imbalance theory in the video Do You Have a Chemical Imbalance, which you can view at: **youtu.be/ARZ2Wv2BoFs**

When people with unmet social, physical, emotional, mental, and spiritual needs are told they have a "disease" such as depression, and that it is caused by a chemical imbalance, the primary help offered is pharmacological in nature. In
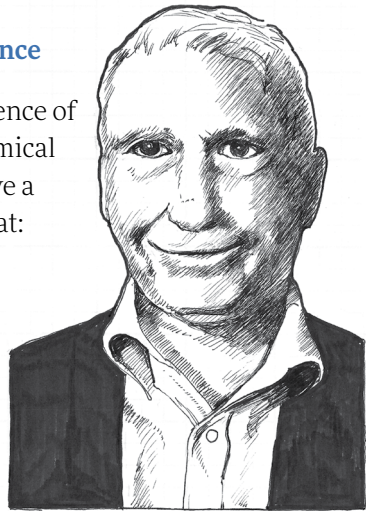
Dr. Peter Breggin

many cases, social supports (such as disability income) are not offered unless an individual accepts a psychiatric diagnosis and the "standard of care" (psychiatric drugs), often for life.

Challenging the Medical Model

Medical Model Produces Dismal Outcomes

Psychiatrists should be concerned about the dismal outcomes experienced by psychiatric patients in the West. A ten-year study by the World Health Organization (WHO) shows that people with "schizophrenia" in third world countries enjoy significantly better recovery rates than people in Western nations. Source: **mindfreedom.org/who-study-schizophrenia**

The medical model holds that people with schizophrenia cannot recover because it is a chronic brain disease. Since there is no "cure," it must be "managed" for life with tranquilizers known as neuroleptics. The data does not support this gloomy outlook, but it is the narrative routinely conveyed by practitioners of the medical model to their patients.

The Harrow Study undermines this narrative by showing better long-term outcomes for unmedicated people diagnosed with schizophrenia than medicated people with the same diagnosis. Critics dismissed this study on the basis that it was "naturalistic" until Dr. Wunderlink duplicated Harrow's findings in a randomized, placebo controlled experiment. View a summary of both studies: **mindfreedom.org/ evidence-based-psychiatry-display**. The article also lays out the argument in general against antipsychotics.

Dr. Loren Mosher, MD

In 1979, Loren Mosher, MD, challenged the medical model of "psychosis" by conducting a groundbreaking experiment called Soteria. He compared the outcomes of two groups of individuals, all of whom were diagnosed with schizophrenia, using two completely different approaches.

His experiment resulted in strong evidence that those who are supported by nonmedical staff with no-drug/low-drug approaches in a homelike environment for several months enjoy better long-term outcomes than those who receive standard treatment in a locked psychiatric hospital with standard doses of maintenance neuroleptics. See the chapter in Tree section "Soteria" for more information.

Dr. Mosher's scientific contributions went unacknowledged for the most part, and his Soteria study was not widely published in the medical literature. But psychiatric survivors consider his contributions to be a milestone in the movement for human rights. Read a tribute to Dr. Mosher by David Oaks, a leader in the psychiatric survivors movement: **mindfreedom.org/tribute-loren-mosher**

Dr. Mosher was sometimes compared to French physician Philippe Pinel, famously known for removing the chains from women in a Paris asylum during the 1800s. More information about Dr. Pinel can be found at: **mindfreedom.org/wiki-philippe-pinel**

"Dissident psychiatrists" such as Dr. Mosher are in good company. Some of the greatest contributions to medical science were made by people who challenged the reigning medical authorities of their time.
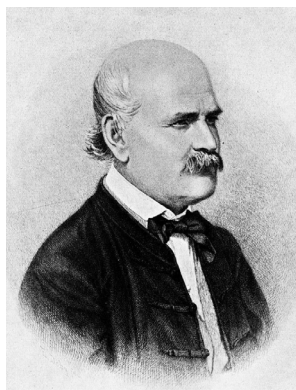
Dr. Semmelweis

A good example of someone who challenged the medical dogma of the mid 1800s is the Hungarian physician Ignaz Semmelweis.

Back then, doctors like Semmelweis were no longer thinking of illness as an imbalance caused by bad air or evil spirits. They looked instead to anatomy. Autopsies became more common, and doctors got interested in numbers and collecting data.

Dr. Semmelweis

The young Dr. Semmelweis was no exception. When he showed up for his new job in the maternity clinic at the General Hospital in Vienna, he started collecting some data of his own. Semmelweis wanted to figure out why so many women in maternity wards were dying from puerperal fever—commonly known as childbed fever.

He studied two maternity wards in the hospital. One was staffed by all-male doctors and medical students, and the other was staffed by female midwives. And he counted the number of deaths on each ward.

When Semmelweis crunched the numbers, he discovered that women in the clinic staffed by doctors and medical students died at a rate nearly five times higher than women in the midwives' clinic.

After going through a process of elimination, he observed that the male medical students were routinely performing autopsies, then going straight from the autopsy hall to delivering babies.

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Semmelweis wondered if little pieces of corpse from the autopsy procedure might be transferred to women during delivery. He ordered his medical staff to start cleaning their hands and instruments not just with soap but with a chlorine solution. Chlorine, as we know today, is about the best disinfectant there is. Semmelweis didn't know anything about germs. He chose the chlorine because he thought it would be the best way to get rid of any smell left behind by those little bits of corpse. His procedures resulted in a huge reduction in mortality rates, but when he attempted to get other doctors to adopt his procedures, he was ridiculed and ignored.

Semmelweis ended up in an asylum, where he died two weeks later from septicemia.

> "Much biographical material has been written on Semmelweis, yet the true story of his death on 13 August 1865 was not confirmed until 1979, by Nuland. After some years of mental deterioration, Semmelweis was committed to a private asylum in Vienna where he died of major injuries that could only have been sustained in beatings to which Semmelweis had been subjected while in the asylum. Semmelweis was severely beaten by the asylum guards and then left essentially untreated."—(Carter, 1995, p. 268)

The medical model of treating people in distress has failed to produce any scientific evidence such as genetic markers, blood tests, scans, etc. that can reliably predict any mental health disorder. It has failed to produce better outcomes than alternative models for treating people.

Yet it continues to serve as the foundation for nearly all mental health research, policies, laws, and clinical treatment in Western industrialized countries.

Non-medical Models

Social and Psychological

By far, the most effective approaches to supporting people who have mental and emotional challenges are those that emphasize personal agency, empowerment, and social inclusion. Soteria and the Hearing

Voices Movement are excellent examples. These promising models are covered in much greater detail in the Tree section.
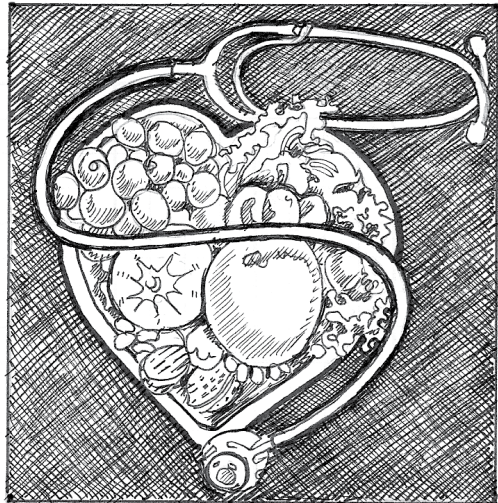
Physical and Somatic Treatments

Body Centered Therapy

According to Psychology Today, somatic therapy is a form of body-centered therapy that looks at the connection of mind and body and uses both (**mindfreedom.org/what-is-psychotherapy**) and physical therapies for holistic healing. In addition to talk therapy (**mindfreedom.org/what-is-psychoanalytic-theory**), somatic therapy practitioners use mind-body exercises and other physical techniques to improve their patient's physical and emotional well-being.

Interest in somatic approaches to mental wellness is on the rise. Small clinics like the Amenda Clinic (**amendaclinic.com**) are cropping up to meet the demand. Google terms like "integrated medicine" to find somatic mental health providers in your community who use such approaches.

Nutrition

Some advocates claim that improved nutrition would eliminate the need for many psychiatric interventions. Julia Rucklidge, a psychologist, presents positive data on nutritional approaches to a variety of mental health disorders ranging from ADHD to schizophrenia. View her lecture at: **mindfreedom. org/surprising-nutrition- mental-health-video** and watch Dr. Rucklidge's response to being flagged by TED Talks: **mindfreedom.org/why-scientists-reconsider-tedtalk**

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Some psychiatric survivors, justifiably concerned about being stigmatized by yet more claims that their brains are "inflamed" or "deficient," scoff at nutritional approaches. Yet other survivors claim to have been enormously helped by this approach.

Individual stories of recovery involving "orthomolecular" approaches can be very compelling. One psychiatric survivor claims to have suffered from years of suicidal thoughts, delusions, and auditory and visual hallucinations until she replaced a cocktail of psychiatric drugs with niacin (B3 vitamin) therapy. Her story of recovery can be read at: **mindfreedom.org/schizophrenia-deconstructed**

Early pioneers of nutritional approaches include Abram Hoffer, MD, who used orthomolecular approaches to successfully treat patients who had been diagnosed with schizophrenia. Read one of his published studies: **mindfreedom.org/ proper-treatment-schizophrenia-vitaminb3**

For more information about a large range of alternative mental health treatments including orthomolecular approaches, visit Safe Harbor at: **alternativementalhealth.com**

Psychotherapy

One of the best ways to support people in distress is by listening. Often, people in distress find it helpful to meet regularly with highly trained therapists who are capable of listening without judgement and can offer helpful feedback. There are over fifty kinds of therapeutic approaches that fall under the broad category of "talk therapy" or "psychotherapy." A small number are highlighted below.

Cognitive Behavioral Therapy

According to Psych Center, Cognitive behavioral therapy (CBT) is a short-term, goal-oriented psychotherapy treatment that takes a hands-on, practical approach to problem-solving. Its goal is to change patterns of thinking or behavior that are behind people's difficulties, and so change the way they feel: **mindfreedom.org/cognitive-behavioral-therapy**

For many decades, many mental health professionals dismissed cognitive behavioral therapy as a useful primary "treatment" for people labeled "psychotic." Ron Unger, a cognitive behavioral therapist, has trained hundreds of psychologists, counselors, and social workers on the benefits of this approach. His learnings from years of private practice can be found on his blog: **mindfreedom.org/ron-unger**

Ron Unger, LCSW

Acceptance and Commitment Therapy (ACT)

ACT helps clients develop mindfulness skills with the goal of consistent values and psychological flexibility. View a video on ACT and psychosis at: **mindfreedom.org/act-psychosis-video** and a webinar by Eric Morris, an ACT therapist, researcher, and author at: **drericmorris.com/presentations**

Process-Oriented Psychology

Process-oriented psychology (**mindfreedom.org/wiki-process-oriented-psychology**) originated in the 1970s by Arnold Mindell, an American Jungian analyst, then living in Switzerland.

According to Wikipedia, Process Work is described as an integrative and holistic approach to understanding a range of human behaviors. It is characterized as creative and improvisational: a "fluid, flexible, playful approach, using some basic principles to improvise effective approaches to whatever comes its way, even-handedly weaving together the personal, political, the bodily, the relational and the spiritual aspects of existence." It is considered to have similarities with Eugene Gendlin's ***Focusing*** (**focusing.org**) and is identified with a focus on the unknown aspects of experience:

> "Process Work . . . seeks to encounter with the unknown and the irrational side of life . . . [It] appreciates symptoms and disturbances of any sort, not as pathologies to be healed or transcended or somehow got rid of, but as expressions of the

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very thing we need for our further growth, happiness, or enlightenment."—Linda Hartley, Somatic Psychology (2004)

An excellent article by Ron Unger on process-oriented psychology: **mindfreedom.org/process-oriented-approaches-extreme-states**

Contemplative Psychotherapy

This approach integrates Buddhist teachings and Western psychotherapy to focus on self-awareness (**mindfreedom.org/self-awareness-better-life**), improve overall health, and use wisdom to heal. For more information on this approach watch: **youtu.be/zB5tacmLUnI**

Energy Medicine and the Emotional Freedom Technique

"The last twenty-five years have welcomed an integration of Chinese medicine with psychotherapy, by tapping on acupressure points along with identifying specific individual issues and goals. This powerful tool can dramatically help transform emotions and release trauma."—Harriet Cooke, MD

Well-documented research can be found on the Association for Comprehensive Energy Psychology website: **energypsych.org**
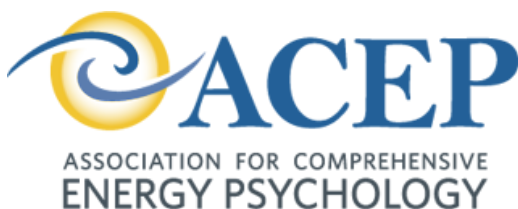
Items for Action

Study other models for framing human distress and join in group discussions on:

facebook.com/groups/the.shamanic.view.of.mental.illness

Read and distribute the following books to fellow organizers:

- *Deadly Medicines and Organised Crime: How Big Pharma Has Corrupted Healthcare* by Peter Gotzsche
- *Psychiatry Under the Influence: Institutional Corruption, Social Injury, and Prescriptions for Reform* by Robert Whitaker

Notes:

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Treatment by Force

Treatment by force is a euphemism for social control. Disguising it as "medicine" only serves to help advocates of forced "treatment" conflate the long-term benefits of forced drugging and shock, while covering up the harm it inflicts.
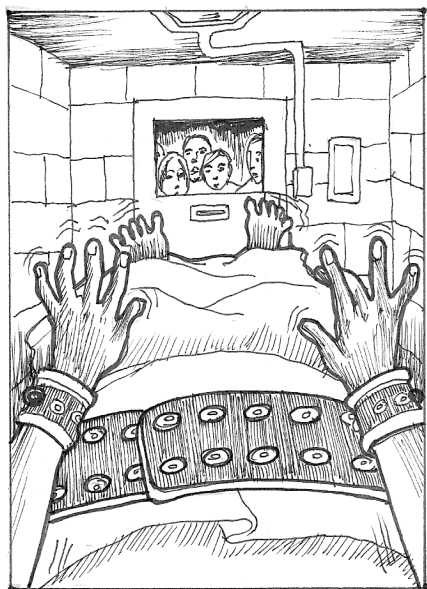
"I went to the mental health system for help with my emotional distress and they responded by hospitalizing me and retriggering the trauma of helplessness. I fought the restraints and seclusion because it only served to retraumatize me with the same helpless feeling of immobility that was present when I was being raped by my stepfather. The mental health system didn't understand and they continued to try and treat me with painful drugs and other things that didn't help."—Pat Risser, mindfreedom.org/personal-stories/risserpat

"I'm a psychiatric survivor, and I don't use that term loosely. I have been stored in warehouses labeled hospitals. I have endured weekly lectures termed therapy. I have been zapped until my brain burns white. I have been held down, tied down, put down. I have had pills forced down my throat and needles plunged into my flesh. All this to make me 'normal,' a mold I will never fit."—Jody A. Harmon, mindfreedom.org/personal-stories/harmonjodya

Thea Amidov lays out five basic arguments against treatment by force in the article *"Uncivil Commitment: Mental Illness May Deprive You of Civil Rights,"* featured in PsychCentral:

1. There is no reliable methodology behind the decision of whom to commit.

2. Confinement does not offer effective treatment.

3. Involuntary psychiatric hospitalization is often a damaging experience.

4. Involuntary confinement undermines the patient-doctor relationship.

5. Finally, coercive treatment of people with mental illness is discriminatory: **mindfreedom.org/mental-health-civil-rights**

Even though the number of people detained in large state-run mental hospitals has declined dramatically since the 1950s, hospitals still play a critical role in treatment by force by serving as the "on-ramps" in the community.

As recently as the 1950s, treatment by force involved the use of procedures known to cause death and permanent disability, such as lobotomies and insulin-induced comas.
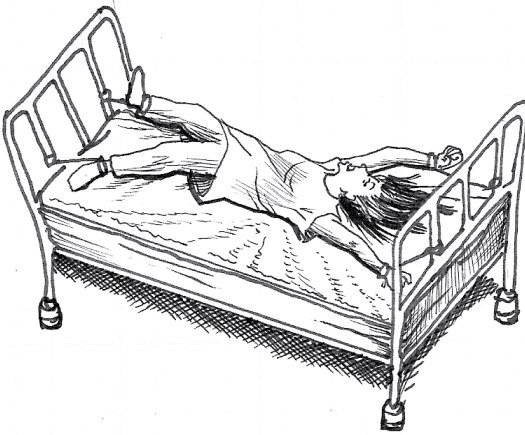
Today, most treatment by force consists of forced drugging and shock. It is often court ordered, taking place in the community, outside the confines of a hospital. People who resist court-ordered drugging can lose their housing and freedoms, and face incarceration.

In the United States, court-ordered treatment outside a hospital is commonly referred to Assisted Outpatient Commitment (AOT). In the United Kingdom, a person is said to be "sectioned."

AOT is a form of treatment by force and can be applied to people who have broken no laws. It is often initiated when people who experience a

mental health crisis are transported to the emergency room of their local hospital and then confined (locked up) due to lack of options.

When someone is experiencing a crisis involving difficult emotions, their family members, friends, or neighbors may panic and call the police. First responders often lack training in de-escalating situations involving difficult emotions. A person may arrive at a hospital in a highly agitated state, handcuffed or restrained in a gurney, often due to faulty interventions by family members and first responders.

Sometimes family members or friends may "coax" a loved one in crisis to accompany them to the ER voluntarily. Once there, family members may apply pressure on staff to prevent their loved one from leaving. Most hospitals heavily weigh the say-so of a police officer or a family member when determining if a person meets the legal threshold required for treating someone against their will.

Often family members are ignorant of the psychological or physical harm that may result from treatment by force. They do not know that nondrug, nonforce alternatives have been shown to be more effective in the long run. They may exaggerate their loved one's behavior to secure a "bed" in a psychiatric hospital, thinking that it is better than having their loved one in jail or on the streets.

"If you are diagnosed with schizophrenia, they talk with you like you are not there. They talk about you but not with you, but you have to hear it. But if you really want to talk, the doctors and nurses in the hospital don't have time for a conversation."

–Beate Braun

mindfreedom.org/personal-stories/braunbeate

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"I remember my first drive to McLean. The grounds looked so beautiful that I thought to myself, 'You know, I really could use a nice rest . . .' But when I first arrived at the ward—Bowditch—I found the atmosphere to be highly authoritarian and stressful. I also found out one seldom saw the grounds because all the buildings were connected by lots of tunnels. Within minutes of arrival I was put on a behavior modification plan, where I had to spend a certain number of minutes alone in my room, and a certain number of minutes on the ward. That didn't go over very well with me.

I remember sitting on my bed. A staff member repeatedly insisted I 'take my medication.' They pushed a cup of liquid psychiatric drugs in front of me over and over and over. And over again. I finally said, 'Okay, I'll take the medication.' The staff person breathed a sigh of relief and handed the cup to me, which I took . . . and proceeded to pour on the floor. Very quickly I experienced my first gooning: the staff dragged me into a solitary confinement cell, held me on a bare mattress, forcibly injected me in the ass, and then left me in the cell.

When I got out of the cell I felt so overwhelmed. Staff wanted me to clean up the liquid Thorazine that I had spilled on the floor. In an act of defiance to try to shock my captors, I used one of the few things I had that was my own—I used my hair to clean up the spill.

I ended up in the solitary confinement cell—which they called the quiet room— at other times, too. It was during one of those stays that I remember looking out through one of those impenetrable metal window screens . . . I pounded on the screen with my fist and vowed to do something for human rights once I got out.
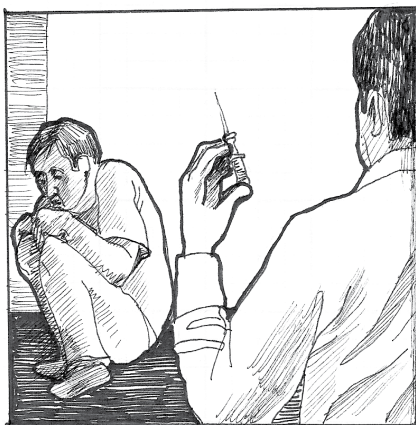
I experienced forced neuroleptics as torture. The harder I tried to think, the harder it was to think. The more I tried to move my body, the harder it was to move my body. I could understand some overwhelmed person choosing to take them. But for me, it was like taking a wrecking ball to the cathedral of thoughts, feelings, and experiences that defined me at that moment. It was incredibly intrusive. I could feel how the chemical affected my vision, my movements, my thoughts. I had terrible paroxysms of my muscles. I became familiar with the list of hazards. I definitely did not want this chemical in me."—David Oaks, mindfreedom.org/personal-stories/david-w-oaks-d1

"Probably the worst experience in the system happened to me just before Christmas in 1998, when I was sent to Portland Adventist Hospital. They had me in isolation and wouldn't allow me to use the bathroom, so I was forced to relieve myself on the floor. When I pounded on the door, demanding to go to the bathroom, a dozen staff came in and took me down.

Two of them beat me, slamming my head over and over against the floor and against a metal half ring that was used for restraints. Because I was begging for mercy, one man put his forearm across my throat, crushing off my ability to breathe. A woman I consider an angel got them off me.

It turned out that the beating had ruptured a neck disk into my spinal cord and I would need surgery. But when I returned home to Corvallis, the mental health workers there didn't give a damn about what happened to me."—Jody A. Harmon, mindfreedom.org/personal-stories/harmonjodya

"When my daughter, a loving and creative artist, experienced a spiritual emergency, complicated by recreational drug use and childhood trauma, she became extremely anxious and confused. I tracked her down while she was wandering the streets. I brought her to the ER. I lived to regret that decision. Years later, my daughter shared that she 'died' that day. I believe her. They transported her to the locked secure ward of the psychiatric wing of the

hospital and on a five-day 'hold.' Since it fell on a three-day holiday, it turned out to be more like ten days. The things that happened to her in the next ten days at the psychiatric unit of the Catholic-run private hospital deeply harmed her. I regret the role I played.

When she arrived at the ER, what little was left of her dignity, confidence, and personal boundaries was taken away. She was stripped, restrained, and sedated that only served to make her more agitated. She experienced paradoxical effects to the drugs they pumped into her. The longer she stayed in the hospital, the more drugs they gave her, and the more drugs they gave her, the more out of touch with reality she became. The psychiatrist took only five minutes to talk to me and my husband. He babbled on about his brand loyalties, and became angry when I brought up the issue of my daughter's rights. He appeared to have zero training in dealing with disturbed people and at that point I would include myself as very disturbed. The only difference was that I was able to go home and deal with my disturbance in the comfort of my own home that night, and I wasn't being pumped full of neurotoxins. That is the day that I started to develop a fear of psychiatrists and their unmitigated power to harm people, a fear that continued to exist ten years later.

When my daughter refused to take the drugs voluntarily, she was restrained and injected by force. Years later, she shared that being held down and injected was like being raped. When they released her ten days later, she was shaking, agitated, angry, disoriented, and in far worse condition mentally and emotionally than when she entered. So was I. Detoxing from powerful neuroleptics, with no support, she went back to her apartment and nearly immediately committed a nonviolent crime involving damage to a neighbor's property. The authorities put her back in the hospital, this time under civil commitment for 180 days with the recommendation that she be sent to the state hospital.

This started a ten-year vicious cycle of treatment by force: running away from psychiatric facilities and foster homes, and cold-turkey withdrawals. Unlike in detox facilities where people trying to wean off opiates and narcotics do so in highly supported rehab facilities, my daughter was forced to wean off meds without any support. During those times, she would end up lost or disoriented on the streets, only to be rounded up by police. Sometimes she would simply turn herself in to be 'voluntarily' readmitted. Back in the familiar setting of the hospital, she would be put back on high doses of sedating neuroleptics and receive long lectures about her 'permanent illness' and the need for her to be med compliant. All of this had the effect of driving her further inside herself and undermining her self-confidence.

While heavily drugged to 'stabilize,' she would drool and shuffle like someone intoxicated on alcohol. She was frequently incontinent, lethargic, unable to read, write, converse, draw, play music, or participate in the most basic activities of daily living. She would often sleep for sixteen to eighteen hours daily. No one can live like this. Psychiatric drugging creates unbelievable trauma and dissociation. I think we have only begun to understand the level of iatrogenic harm routinely meted out in the form of treatment by force to those who are sensitive to the effects of drugs or whose behavior is 'different.' I believe we must protest treatment by force vigorously and deliberately until we take our last breath on this earth."
—mother of psychiatric survivor

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"Ceremony of degradation" is the term used by Dr. Loren Mosher to describe treatment by force and confinement. Modern psychiatric hospitals are similar to prisons in that behavior is modified and regulated by force or threat of force, creating a culture of despair, hopelessness, anger, and distrust. The "crime" committed by the psychiatric "inmates" is exhibiting socially unpopular behavior or holding strange beliefs.

Solitary confinement, the presence of locks, bars, and alarm systems, the lack of privacy, and the deprivation of all of a person's belongings can be terrifying and lead to loss of personal agency. Taking away someone's agency can quickly compound, prolong, or worsen their emotional anguish.

Common Features of Psychiatric Hospitals

· Nurses and other workers work in concrete bunkers centrally located in the common areas so that they can see everything in the common area without having physical contact with patients. Patients usually interact with nurses by speaking loudly into a speaker built into the glass walls.

· Solitary confinement and five-point restraints are used to deal with disruptive behavior, reinforcing helplessness.

· Doors and hallways are locked. Alarm systems, surveillance cameras, and security guards reinforce fear and paranoia.

· Rooms are windowless or have windows with bars.

· Few opportunities exist to enjoy nature. Few facilities have outdoor

spaces for fresh air, and if they exist, they are typically small exercise yards surrounded by high brick walls or barbed wire.

· Privileges such as soda pop or a few minutes of fresh air daily are used as carrots to modify people's behavior, a highly infantilizing approach that treats adults like naughty children.

· Lack of privacy is common. Even a patient's sleeping area is monitored with mounted video surveillance cameras. This can create paranoia where none existed.

· Facilities lack curtains, pillows, rugs, and other household items typically associated with comfort or leisure.

· Couches and chairs are indestructible. Many times they are outdoor grade-heavy plastic or solid metal welded to the floor. Beds are often mattresses on the floor.

· Institutionalized food is served with plastic, paper, or Styrofoam service and cutlery.

· Body cavities are routinely examined, by force if necessary, for illegal drugs and weapons upon admission, even if a person does not have a history of violence or illegal drug use.

· Patients in examination rooms are routinely threatened with restraints, injections, or loss of privileges if they are not cooperative.

Lack of Amenities

Patients in the psychiatric ward end of most hospitals are denied amenities enjoyed by patients at the same hospital, such as cancer patients. For example:

· No outside food may be brought to psychiatric patients by their loved ones, even if a patient has particular ethnic, Kosher, gluten-free, or dairy-free needs.

· Comfort objects such as personal phones, blankets, and street clothing are taken away, along with any possessions that are important to a person's identity.

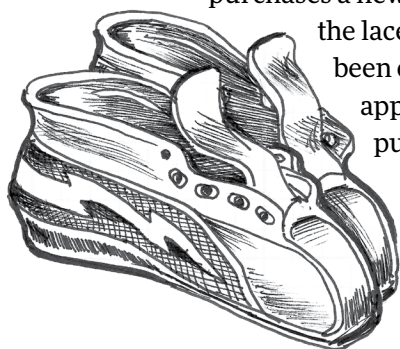· Visits are restricted. Visiting hours are often limited to one hour per

day, and the visits are usually not private. Visitors are searched for weapons, phones, etc.

· The only clothing allowed are hospital scrubs or donated sweats and plastic flip-flops.

· Personal hygiene products are meted out as needed in plastic cups. To obtain feminine hygiene products, a patient must contact a nurse in a "nursing station" by speaking loudly in a speakerphone, in full view of other patients.

· Patients may use the telephone only by request and all phone calls take place in full view and within earshot of other staff and patients.

· Patients must form lines to receive food and drugs.

· Games, books, and musical devices are locked up and their use is highly regulated.

"After years of living in institutions, my daughter finally came home. Reintegrating into society is a slow process after someone has been institutionalized. Every time my daughter purchases a new pair of tennis shoes, she removes the laces. Even though she has always been concerned about her personal appearance, she prefers to walk in public with the tongues of her shoes flopping around ridiculously. By removing her shoelaces she is signifying that she is compliant; this is the essence of institutionalization, to teach conformity.

Hospitals blanketed my daughter with 'safety' by removing all external threats from her environment like scissors, cords, knives, matches, etc. while exposing her to harmful psychiatric drugs, even the threat of electric shock, calling these harmful interventions 'therapeutic' and 'helpful.'"—mother of psychiatric survivor

Legal Aspects of Treatment by Force

In the United States, people who experience a mental or emotional crisis may be forced to receive "treatment" for short periods of time at acute care facilities (hospitals or ERs) or for long periods as an inpatient or outpatient if they are deemed to meet the criteria for involuntary treatment.

Most Western industrialized countries have provisions under the law to legally treat people by force.

Danger to Oneself or Others

In 1975, the US Supreme Court ruled in O'Connor v. Donaldson that people cannot be institutionalized against their will in a psychiatric hospital unless they are determined to be a threat to themselves or others.

This landmark ruling was the result of a lawsuit filed by a psychiatric patient named Kenneth Donaldson. In 1956, Mr. Donaldson traveled to Florida to visit his elderly parents. While there, he reported that he believed one of his neighbors in Philadelphia might be poisoning his food. His father, worried that his son suffered from paranoid delusions, petitioned the court for a sanity hearing. Donaldson was evaluated, diagnosed with "paranoid schizophrenia," and civilly committed to the Florida State mental health system.

At his commitment trial, Donaldson did not have legal counsel present to represent his case. Once he entered the Florida hospital, Donaldson was placed with dangerous criminals, even though he had never been proven to be dangerous to himself or others. His ward was understaffed, with only one doctor (who happened to be an obstetrician for over 1,000 male patients). There were no psychiatrists or counsellors, and the only nurse on site worked in the infirmary.

He spent fifteen years as a patient; he did not receive any treatment, though, actively refusing it and attempting to secure his release. Throughout his stay he denied he was ever mentally ill, and refused to be put into a halfway house.

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Donaldson later sued the hospital and the staff for robbing him of his constitutional rights and he won the lawsuit: **mindfreedom.org/wiki-oconnor-donaldson**. He wrote a book about his experience: **mindfreedom.org/insanity-donaldson**

Recently, the threshold of "danger to oneself or another" established by O'Connor v. Donaldson has been under assault (see "Cures Bill" later in this chapter). A movie (see trailer: **mindfreedom.org/55steps-movie**) explores the issue of forced drugging based on the true story of Eleanor Riese, a mental illness patient who brings a class action suit to give competent mental patients the right to have a say in their drugs while they're in a hospital, and Colette Hughes, the lawyer appointed to her case.

Short Term "Holds"

In the US, hospital staff may authorize that an individual be put on a "hold" during which time they are not allowed to leave.

The average length of time that a person can legally be on a hold is three to five days. If hospital staff want to detain a patient for longer than this period, they generally contact a commitment officer who must schedule a commitment hearing on behalf of a patient. That patient is usually represented by a court-appointed attorney who spends an average of twenty-two minutes with a patient (see chapter "Protection and Advocacy" beginning on page 77).

Civil Commitment

Even when no crime is involved, most states in the US have legal mechanisms in place to forcibly treat people for longer periods through "civil commitment." The length of time for civil commitment varies from state to state. The average length is 180 days. Forced treatment under civil commitment may be "inpatient," such as in acute care facilities, state mental hospitals, etc., or in the community, such as in a foster home, a person's apartment, etc.

As mentioned earlier, court-ordered treatment in the community under a civil commitment period is euphemistically called "Assisted Outpatient Treatment" (AOT) or "Asserted Community Treatment" (ACT).

Forensic Commitment

In the US, if a person is charged with a crime, during an arraignment hearing a judge may order an individual to undergo a psychological evaluation to ensure that they are able to assist in their defense.

If a person is determined to be unable to assist with their defense, that person may be ordered to remain in jail or a hospital and be treated by force (by drugging) to "restore" that person's competency.

A person convicted of a crime and determined to be "insane" during the commission of that crime is subject to a form of forensic commitment, usually subjecting them to treatment by force for a very long time, depending on the state.

Resources for People Receiving Treatment by Force

Very few attorneys are knowledgeable and willing enough to help a client fight harmful treatment by force, let alone on a pro bono basis. Clients who often lose everything—their jobs, housing, etc.—as a direct result of being involuntarily confined for extended periods often have very few resources to fight court-ordered treatment.

MFI receives a crushing volume of calls from people who want to know how they can exercise their right to refuse forced drugging or shock, while confined or living peaceably in the community.

See MindFreedom International's **Forced Drugging Defense Packet** available at madmarket.org. The packet consists of signed affidavits by medical professionals providing proof of harm caused by neuroleptics. These affidavits are usually admissible as evidence in an involuntary commitment hearing.

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The following chapters "Disability Rights" and "Protection and Advocacy" cover more resources under the Americans with Disabilities Act. MFI also refers people to the following organizations for legal information:

Psych Rights is a nonprofit, tax-exempt public interest law firm founded by attorney and psychiatric survivor Jim Gottstein. The Psych Rights mission is to mount a strategic litigation campaign against forced psychiatric drugging and electroshock in the US akin to what Thurgood Marshall and the NAACP mounted in the 40s and 50s on behalf of African American civil rights. **psychrights.org**

"The National Association for Rights Protection and Advocacy (NARPA) mission is to promote policies and pursue strategies that result in individuals with psychiatric diagnoses making their own choices.

We educate and mentor those individuals to enable them to exercise their legal and human rights with a goal of abolition of all forced treatment."

NARPA exists to promote social justice for people who experience the world in ways society often calls "mentally ill." Their efforts consist mainly of education and advocacy, and they host an annual conference to advance rights and alternatives to coercive and harmful practices. **narpa.org**

Legal Representation of People Being Treated by Force

From Psych Rights: In a 2007-2008 study of the performance of attorneys representing people facing commitment in San Diego County, California, 16 found the average duration in contested cases was 22.3 minutes, the longest lasting 44 minutes and the shortest 7 minutes. Professor Michael Perlin, the foremost expert on United States Mental Disability Law, has noted, "If there has been any constant in modern mental disability law in its thirty-five-year history, it is the near-universal reality that counsel assigned to represent individuals at involuntary civil commitment cases is likely to be ineffective." **psychrights.org**

International Resources for Forced Treatment
- · Australia: **mindfreedom.org/mental-health-legislation**
- · Summary of Rights under the Mental Health Act in Australia: **mindfreedom.org/summary-rights-australia**
- · England: **nsun.org.uk**

MindFreedom's Shield Program
MFI has a history of effectively harnessing people power to protect people from harmful treatment by force. Read about MFI's Shield Program: **mindfreedom.org/shield**

At this writing, the Shield Program is under reorganization, but MFI continues to accept applications for the Shield protection. Online applications can be found at: **mindfreedom. org/shield-registration-form**. To obtain a mailed copy call the MFI office at **541-345-9106** or USA toll free **1-877- MAD PRID(e)**.

Some of the application questions are similar to the questions on an Advance Care Directive. The information can be kept confidential. It may be used to quickly activate an international network of public alerts if a Shield member is ever threatened with involuntary psychiatric human rights violations.

Ray Sandford: Successfully Shielded with People Power

On October 28, 2008, Ray Sandford called the MindFreedom office. He had asked his local library about organizations that support human rights in mental health. The reference librarian gave him MindFreedom's phone number.

He said that every Wednesday morning he was escorted from his group home to a hospital for another involuntary electroshock, under court order.

MFI investigated and kicked off a public campaign that became global. Issuing twenty-one alerts, MindFreedom's campaign activated thousands of people who peacefully but passionately contacted elected officials, held protests, mailed Ray stationery supplies, won extensive media coverage, visited Ray, and much, much more. At least one elected official said they felt "inundated."

But MindFreedom also found that Ray's oppression was systemic and deep.

MindFreedom volunteers identified and listed on the MFI website more than thirty agencies and individuals receiving taxpayer money to help Ray. Only a few agencies helped him—and most actually opposed his rights. Because MFI's website is so popular, many of those who oppressed Ray can Google themselves and discover their MFI listing near the top.

On May 13, 2009, Ray was escorted all the way to a hospital bed. He was prepped for another forced electroshock. Because of the outrage of activists, hospital authorities cancelled Ray's shock at the last second, and he was sent home.

More victories quickly followed.

Ray's psychiatrist quit because he said his insurance company was concerned about all the public attention. MindFreedom helped Ray find a new psychiatrist supportive of Ray's human rights.

Ray's family even joined in the campaign. MindFreedom organized a YouTube video with Ray and his mom, begging for the shock to end. Ray's guardians, an agency under the Evangelical Lutheran Church in America (ELCA), tried to stop the video from going public, but it failed.

Ray's family found a better attorney, and Ray found great pleasure in firing his ineffective court-appointed attorney.

Several concerned Minnesota agencies formed an ECT Work Group to change the law in Minnesota. Two MindFreedom representatives serve on the committee.

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"Psychiatrists lie when they say patients lack insight, as if this putative lack of insight is the same as literal unconsciousness. Psychiatrists lie when they assert that adults are children. And psychiatrists lie when they say they can accurately predict who is going to harm themself and others."

–Jeffrey A. Schaler

"Mental Health and the Law" Cato Unbound: A Journal of Debate,
August 17, 2012
mindfreedom.org/mental-health-law-cato

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Anosognosia

The term anosognosia has done more to harm people than any other label. It is used to justify treatment by force, and it lacks scientific merit.

According to the website of Treatment Advocacy Center, an organization that promotes legislation to expand forced drugging and shock:
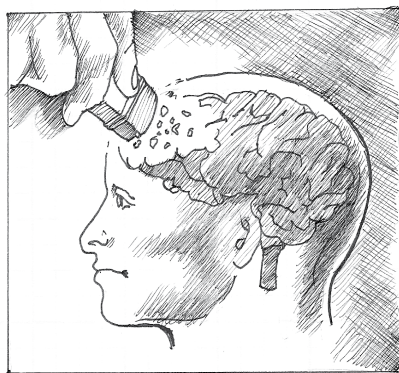
> "Anosognosia, also called 'lack of insight,' is a symptom of severe mental illness experienced by some that impairs a person's ability to understand and perceive his or her illness. It is the single largest reason why people with schizophrenia or bipolar disorder refuse medications or do not seek treatment."

Dr. Sandra Steingard, a psychiatrist who is openly critical of her own profession, states:

> "As with the notion of 'chemical imbalance,' the term anosognosia has crept into the psychiatric lexicon. Its use confers a certain sophistication of understanding and knowledge that is not supported by the data."
> Source: mindfreedom.org/anosognosia-conjecture-fact

The Opposition to Choice and Alternatives

Proponents for treatment by force are working tirelessly to undo the rights that psychiatric survivors have dedicated their lives to winning, namely the right to have choices and alternatives in the mental health system. Two of the most prominent proponents of treatment by force in the US are:

· E. Fuller Torrey, a psychiatrist whose work is entirely funded by the Theodore and Vada Stanley Family Foundation: **treatmentadvocacycenter.org**

· D.J. Jaffe of Mental Illness Policy Org: **mentalillnesspolicy.org**

Torrey and Jaffe both claim that individuals who refuse mental health "treatment" (i.e. forced drugging and shock) do so because they have anosognosia. Both fabricate statistics involving a population of people they call the "untreated mentally ill," a category that the government and most researchers do not recognize.

Conflating Violence to Push Forced Treatment

Torrey and Jaffe claim that the "untreated mentally ill" are more likely to be violent than their treated counterparts. Their goal is to expand treatment by force in every state. In 2016, they focused on creating what is known as the "Murphy Bill."

Jaffe's background is in advertising. In 1994 he stated, "From a marketing perspective, it may be necessary to capitalize on the fear of violence to get the law passed." Source: *"Fear Tactics in Advocacy: 15 Examples"* **mindfreedom.org/fear-tactics-in-advocacy**

At the 1999 annual conference for the National Alliance on Mental Illness (NAMI), Jaffe stated, "Laws change for a single reason, in reaction to highly publicized incidents of violence. I am not saying this is right, I'm saying this is the reality . . . it means you have to take the debate out of the mental health arena and put it in the criminal justice/public safety arena."

These words, written by Jaffe in 1993, launched a campaign known now as the Treatment Advocacy Center in Arlington, Virginia, to toughen involuntary outpatient commitment laws throughout the US.

Jaffe's rhetoric routinely exploits public fear. His tactic of conflating statistics pertaining to crime, violence, and the "mentally ill" has been very effective in reframing the argument away from the patient's experience of treatment by force to the public's supposed need for protection against these "psychotic" individuals. A critique of his tactics can be found in Phyllis Vine's article *"Fairness and Accuracy in Reporting"* **mindfreedom.org/mindless-deadly**

Study Shows Treatment by Force Does Not Reduce Hospitalizations

A randomized controlled study shows the ineffectiveness of treatment by force to reduce hospitalizations:

mindfreedom.org/lancet-community-treatment

Study Shows Few Benefits of Treatment by Force

According to Dr. Toby Watson, Clinical Director of Associated Psychological Health Services Inc.,

> "There are no instruments that can accurately identify people at high risk for committing violent incidents and for every one person correctly identified, 5,000 people might be incorrectly identified (false positive) as high risk of homicide.

> There are few studies that have attempted to determine the effectiveness of Outpatient Commitment Orders (OPCs) by comparison to the tens of thousands of OPC ordered, and I wish to highlight all these profound conclusions contained within the studies that are available for peer review. In one of the first thorough reviews of empirical studies of OPC, Dr. Kathleen Maloy concluded in 1992, there was 'almost no valid empirical evidence in support of the effectiveness of involuntary outpatient commitment vis-à-vis treatment compliance, success in the community for people with severe and persistent mental illness.'"

> Dr. Watson continues: "This acknowledgement by Maloy in 1992 led Duke University researchers in North Carolina in 1999 and 2001 to examine if OPC reduced hospitalizations. They, Swartz and his colleagues, concluded 'outpatient commitment had no clear benefit unless it was sustained for at least six months and accompanied by high-intensity community services and supports,' despite no significant differences in hospitalizations between the non OPC controls and those under commitment at the one year mark.

In turn, the Bellevue Outpatient Commitment Study was conducted in 2001, which was the only controlled study that explicitly provided and offered enhanced community services to both OPC and non OPC groups. They reviewed if commitments were necessary for individuals to continue with treatment if they were offered it without the OPC. They concluded 'individuals provided with voluntary enhanced community services did just as well as those under commitment orders who had access to the same services.' Researchers found no additional improvement in patient compliance with treatment, no additional increase in continuation of treatment, and no difference in hospitalization rates, lengths of hospital stay, arrest rates, or rates of violent acts." Read more from Dr. Watson's article: mindfreedom.org/dr-watson-commitments

Cures Bill

Excerpt from the article *"Seven Reasons Why the US's New Mental Health Law Is Dangerous"* by Noel Hunter, Truthout | Op-Ed, Published December 15, 2016 mindfreedom.org/seven-reasons:

"This week, President Obama signed the 21st Century Cures Act, touting the bipartisan mental health measure as 'bringing to reality the possibility of new breakthroughs to some of the greatest health-care challenges of our time.' However, the reality behind this legislation is not quite what it appears to be.

The 21st Century Cures Act will increase the ease with which individuals can be involuntarily hospitalized in a locked ward, increase funding for institutionalized settings, and demand that states implement forced outpatient treatment in order to receive funding. Many media reports are suggesting that it will fix a broken mental health system, incorporate patient voices into clinical processes, decrease mass violence and modernize clinical trials. But will it really? Here are seven reasons why Obama's signing of the 21st Century Cures Act is less than grounds for celebration.

1. Sandy Hook and other tragedies will not be avoided by the measures contained in this bill.

2. The 'reform' actually sets back many advances made in the 20th century.

3. It does not help people live in the community.

4. No extra money is going towards helping people.

5. Effective treatment is not the focus of this bill.

6. This bill is not based on the advocacy of users of mental health services.

7. Pharmaceutical greed and conflicts of interest underlie everything about this bill."

Arguments Against Treatment by Force

Advocates for ending involuntary treatment are not espousing that there should be no supports and services offered to people who are experiencing emotional or mental distress.

On the contrary, the richest nations in the world have an obligation to support and protect their most vulnerable, including individuals with disabilities or individuals experiencing emotional or mental distress. Involuntary treatment involves loss of personal agency, loss of personal freedoms, and usually involves forced drugging or shock.

There should be choices and alternatives in the mental health system so people can avoid potentially harmful drugs and be supported in ways that allow them to maintain the highest degree of control over their lives.

It is not surprising that the momentum for the movement to create options for people in crisis without the use of force and coercion generally originated from psychiatric survivors, peer activists, and their allies starting in the 1980s. Many of the models they created are still in place today and have proven to be more effective and humane in the long run. See the chapters "After a Diagnosis" and "Alternative Ways of Supporting People in Distress" to learn about ways to expand alternatives to forced treatment in your community.

Read *"Supporting Resources: 'The Case for 100 percent Voluntary'"* by Sarah Knutson in Mad In America, February 15, 2016 **mindfreedom.org/case-100percent-voluntary** on the following subjects:

1. These issues are universal not medical
2. Clinicians are lousy predictors
3. Drugs, at best, are problematic
4. Promising alternatives are not being considered
5. Natural diversity is not a pathology
6. This is about trauma, not disordered brains
7. Do the math—it adds up to "voluntary"
8. The continued prejudice against people with psychosocial disabilities is not worthy of a free society.

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Items for Action

Consider organizing a "Truth and Reconciliation" event to expose family members and mental health professionals to the stories of survivors of treatment by force. Here are a couple examples:

May 14, 2016—Mad in America Initiatives *"Truth and Reconciliation: An Evening of Sharing and Healing"* by Rachel Levy, LCSW.

May 25, 2016—KBOO Radio: *Truth & Reconciliation in Mental Health.* Host, Paul Roland, interviews Cindi Fisher, Ptery Lieght, & Grace Silvia, facilitators of first Truth & Reconciliation. (Click the play button at the bottom of the article).

Publicly screen a new documentary entitled *Crazy* by Lise Zumwalt. Invite a range of audience members including mental health professionals by "training" and professionals by "experience" (i.e. psychiatric survivors). Select a facilitator in advance and host a town hall-type discussion immediately following the film to debate the topic of treatment by force. View trailer: **crazythefilm.com/crazy**

Psychiatric Advance Directive

A Psychiatric Advance Directive (PAD) can be an important tool in your empowerment tool kit.

What is a PAD and how does it work? A PAD can help protect you or a loved one from psychiatric harm and abuse.

PADs are relatively new legal instruments that may be used to document a competent person's specific instructions or preferences regarding future mental health treatment.

PADs can be used to plan for the possibility that someone may lose capacity to give or withhold informed consent to treatment.
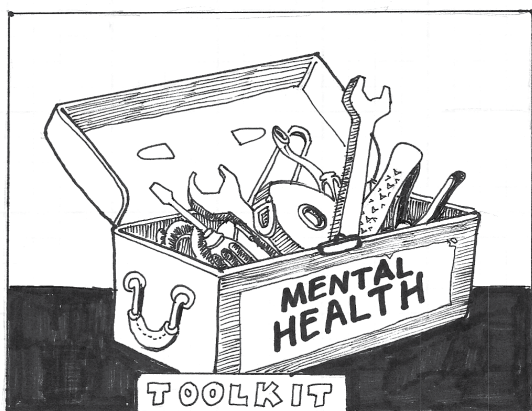
According to Wikipedia: in the US, although twenty-five states have now passed legislation in the past decade establishing authority for PADs, there is relatively little public information available to address growing interest in these legal documents.

As well, in states without explicit PAD statutes, very similar mental health advance care planning can and does take place under generic HCPA statutes—expanding the audience for PADs to all fifty states (see National Resource Center on Psychiatric Advance Directives): **mindfreedom.org/ wiki-psychiatric-advance-directive**

Studies show that only 10 percent of people with a psychiatric diagnosis have completed a PAD. Let's help change this to 100 percent!

To locate the form for a PAD in your state visit: **nrc-pad.org**. If you live outside the US, refer to the "International Resources" below.

For a more thorough introduction to PADs, check out this webcast: mindfreedom.org/intro-pad-webcast. It includes state-by-state information about advance directives, instructions and forms, discussion forums, educational webcasts, current research, links to other websites, and more!

Completing a PAD may have a downside. If you have experienced psychiatric harm, you might not trust the mental health system. You may think that mental health professionals will disregard your wishes because they already consider you to be crazy. Unfortunately, you may be right.

It is true that there is absolutely no guarantee that a mental health provider will honor your PAD 100 percent of the time. But a PAD is your chance to state clearly in writing what you think will harm you and help you. It also gives you an opportunity to list proxies: people whom you trust to help with psychiatric medical treatment decisions in the event of a crisis.

The very act of filling out a form can be triggering. The form may remind you of the huge power imbalance between those who receive treatment by force and those who mete it out.

It may remind you of the cognitive impairment you have suffered as a result of years of forced/coerced drugging.

The harmful and disempowering nature of forced/coerced treatment is not reflected in the clinical nomenclature used in the forms.

The term "restraints" doesn't come close to describing the terror of being shackled to a metal bed, begging for help so you will not pee your pants. "Seclusion" doesn't capture the fear of solitary confinement in a windowless cell for hours on end.

A PAD may require that you identify one or more psychotropic drugs as particularly intolerable, even if you found none of them to be helpful and quite a few to be terrifying.

Perhaps you received twenty different neuroleptics, mood stabilizers, and more over a long period of time, requiring you to go through hundreds of

NUT

pages of medical records to give accurate answers. See Chapter "After a Diagnosis" for instructions on obtaining medical records.

You may feel similarly to a rape survivor having to recount the most painful ordeal of your life in a roomful of strangers. At the same time, completing a PAD can be empowering and help provide a limited amount of closure to painful events. It can also provide you with opportunities to get on the same page with people who support you.

If you want to complete a PAD but need help, you have the right to ask for assistance.

How to Support Someone to Complete a PAD

If you care for someone who you think would benefit from having a PAD on file, consider the following:

- Explain what a PAD is and why it is important.

- Be persistent but not forceful.

- Be patient and plan a generous time frame.

- Consider if the person you are helping has been cognitively impaired by psychiatric drugs or ECT. Do they have difficulty focusing or remembering?

- Ask them if they need technical support.

- Consider the traumatic impact of past psychiatric interventions, especially those involving force. Do traumatic memories make it challenging for them to discuss medical treatments?

- Ask them if they need emotional support.

- If you are a family member, consider seeking help from a peer specialist or counselor to help your loved one complete a PAD.

- Ask if they would prefer to do it as a part of a group.

- Consider learning about Psychiatric Advance Directives together by viewing a webcast on the topic at:
  mindfreedom.org/intro-pad-webcast

- Plan a celebration when a PAD is completed!

In a Hospital and No PAD on file?

If you are on a "hold" or staying for any length of time in a psychiatric unit or state mental hospital and you have not completed a PAD, you have a right to ask for help completing one!

The Joint Commission (**mindfreedom.org/wiki-joint-commission**) on the Accreditation of Healthcare Organizations (JCAHO) *requires* behavioral health facilities to ask patients if they have PADs. The Centers for Medicare and Medicaid Services (**mindfreedom.org/wiki-centers-medicare**) announced that patients have the right to formulate advance directives (**mindfreedom.org/wiki-advance-healthcare**) and to have hospital staff and practitioners who provide coercive hospital interventions comply with these directives.

- If a staff person doesn't ask you about a PAD, notate that failure including any details such as the date of your admission.

- Be proactive. Request access to a computer or the paperwork needed to complete a PAD.

- Notate the date of your request as well as the response of staff to your request.

- Remind them that they are obligated to help you. Failure to do so can put them at risk of losing their accreditation.

- If they still refuse to help you, consider filing a complaint (see the next chapter on how to file a complaint against a hospital). Hospitals that do not honor your PAD risk loss of revenue.

- Remind them that they may lose Medicare (**mindfreedom.org/wiki-medicare**) and Medicaid (**mindfreedom.org/wiki-medicaid**) revenue.

- Be diplomatic but persistent.

- Do not assert your right in a manner that can be construed as violent or offensive, which can put you at risk of losing even more rights!

While there are legal reasons to provide good crisis planning using PADs, the clinical reasons are equally compelling.

If there are no peers on staff who will help you with a PAD, call your nearest Disability Rights Organization in your state (see chapter "Disability Rights" that starts on page 79).

International Resources for PADs

Canada
- attorneygeneral.jus.gov.on.ca
- ontario.ca

United Kingdom
- mindfreedom.org/uk-pad
- mindfreedom.org/uk-mind-health

Ireland
- mindfreedom.org/ireland-pad

Australia
- mindfreedom.org/australia-pad

Japan
- mindfreedom.org/japan-pad

The Protection and Advocacy (P & A) Programs were created to protect the rights of people with disabilities under the Americans with Disabilities Act (ADA). P & A programs were greatly expanded under the ADA. There are six that exist today. To view a comprehensive list of P & A programs view: mindfreedom.org/pa-cap

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Protection and Advocacy Programs

Each state is mandated to have its own P & A program. People who are being held against their will in a psychiatric institution frequently seek legal assistance from MFI to assert their right to live independently in the community without the fear of treatment by force or coercion. MFI often refers them to the P & A organization in their state. To find the one in your state, go to: mindfreedom.org/pa-state-list

PAIMI

Protection and Advocacy for People with Mental Illness (PAIMI) is a P & A program. According to a federal website, PAIMI uses federal grant funds to:

1. Investigate incidents of abuse and neglect on behalf of individuals with mental illness rendering care or treatment in a public or private facility.

2. Pursue administrative, legal (individual and class action litigation), systemic, and legislative activities, or other appropriate remedies, to redress complaints of abuse, neglect, and civil rights violations.

3. Ensure enforcement of the United States Constitution, federal laws and regulations, and state statutes as related to this area.

For information on how to get involved in a PAIMI Advisory Council in your state: mindfreedom.org/paimi

Adequate legal representation for people with disabilities is incredibly important yet remains elusive. According to Psych Rights, most individuals considered to be psychiatrically disabled who are forcibly treated or institutionalized do not receive adequate legal representation prior to and during their commitment hearings:

> "A 2007-2008 study of the performance of attorneys representing people facing commitment in San Diego County, California, 16 found the average duration in contested cases

NUT

was 22.3 minutes, the longest lasting 44 minutes and the shortest 7 minutes.Professor Michael Perlin, the foremost expert on United States Mental Disability Law, has noted, 'If there has been any constant in modern mental disability law in its thirty-five-year history, it is the near-universal reality that counsel assigned to represent individuals at involuntary civil commitment cases is likely to be ineffective.'" View full report on Psych Rights website:

mindfreedom.org/psych-rights-next-level

Find the PAIMI Organization in Your State

Each state has a designated protection and advocacy system that offers advocacy and assistance with legal and civil rights issues pertaining to a disability. To find a Disability Rights Organization in your state visit: mindfreedom.org/DRO-in-your-state

Valididy, an international nongovernmental organization, uses litigation to secure equality, inclusion, and justice for people with mental disabilities worldwide. **validity.ngo**

The National Disability Rights Network (NDRN) works to improve the lives of people with disabilities by guarding against abuse and advocating for basic rights. **ndrn.org**

How to file complaints against quality of care:

Complaints about drug errors, unnecessary or inappropriate surgery, unnecessary or inappropriate treatment, not getting treatment after your condition changed, getting discharged from the hospital too soon, and incomplete discharge instructions and/or arrangements. Find out more here: **mindfreedom. org/medicare-file-complaint**

Disability Rights

Each state in the US has a designated protection and advocacy system that offers advocacy and assistance with legal and civil rights issues pertaining to disability. (See previous chapter "Protection and Advocacy Programs" for more information.)

> To find the designated protection and advocacy system in your state visit the National Disability Rights Network: mindfreedom.org/designated-protection

Protection and Advocacy for People with Mental Illness (PAIMI)

According to the website of the National Disability Rights Network (NDRN):

> "The PAIMI Program was established in 1986. The P&As are mandated to protect and advocate for the rights of people with mental illness and investigate reports of abuse and neglect in facilities that care for or treat individuals with mental illness. The Act was subsequently amended to allow P&As also to serve individuals with mental illness who reside in the community. PAIMI is administered by the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), at HHS."

Olmstead

The **Olmstead** Supreme Court decision **Olmstead v. L.C.** is the most important civil rights decision for people with disabilities in our country's history. This 1999 decision was based on the Americans with Disabilities Act, specifically the "integration mandate," which requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." Source: mindfreedom.org/olmstead

If you are living in a restrictive psychiatric facility such as a state hospital, the Americans with Disabilities Act (ADA) protects your right to live in the "least restrictive" environment within your own community. PAIMI organizations are mandated to provide legal support to people who are denied this right. You can file a complaint under Olmstead by following the instructions below.

Definitions of Disabilities and Language

The Federal Rehabilitation Act (Section 504) lists four categories of mental disabilities: psychiatric disability; retardation; learning disability; or cognitive impairment.

Many mental health treatment providers use the medical model of disability by defining psychiatric disabilities as "diseases" or chronic physical impairments involving the brain. However, many psychiatric survivors reject this definition and do not identify with having a medical disability.

Many psychiatric survivors identify with the social model of disability, which posits that people are not disabled by medical conditions but by barriers and exclusion. For example, using a wheelchair would not necessarily be disabling if every building were wheelchair accessible, and being deaf would not necessarily be disabling if every deaf person had access to ASL interpretation and closed captioning. Similarly, many forms of mental distress and difference would not be disabling if people with these experiences were included and accommodated.

When you or a loved one seek or receive services for disabled people on the basis of a past psychiatric diagnosis, you should consider that there are many models of disability. View a summary of disability models: mindfreedom.org/voices-matter, to adopt a model that aligns with your self-perception.

It is also important, when writing or reporting on people with disabilities, to pay attention to the potential for language to convey stigma or

paternalism. While there is no consensus on how to write about or report on people with disabilities, the following source provides a framework for future attempts to reach a consensus by disability activists: **mindfreedom.org/reporting-guidelines**

When working with other human rights activists and addressing general audiences, it is best to avoid using pathologizing language borrowed from medical literature. More information on the use of language can be found in the Grove section of this handbook.

Organizations That Promote Rights for People with Disabilities

The following organizations are good sources of information related to disability rights and other resources.

· Mental Disability Advocacy Center (MDAC) uses litigation to achieve social change for people with disabilities: **mdac.info**

· National Disability Rights Network (NDRN) works to improve the lives of people with disabilities by guarding against abuse and advocating for basic rights: **facingdisability.com**

· National Council on Independent Living: **ncil.org**

· Bazelon Center for Mental Health Law: **bazelon.org**

· Rooted in Rights: **rootedinrights.org**

· American Association of People with Disabilities: **aapd.com**

· International Disability Alliance: **internationaldisabilityalliance.org**

· ADAPT: **adapt.org**

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United Nations Convention on the Rights of People with Disabilities

The Convention on the Rights of People with Disabilities was passed by the United Nations on December 13, 2006. Read more about it: mindfreedom.org/ convention-rights

According to MFI's website, this development was years in the making: "The International Disability Caucus (IDC), a consortium of more than seventy international, regional, and national organizations of disability rights activists, formed an Ad Hoc Committee at the United Nations to develop a Convention on the Rights of Persons with Disabilities. The World Network of Users and Survivors of Psychiatry (WNUSP) and MindFreedom International worked together as members of the IDC to advocate effectively for the right to self-determination, autonomy, and legal capacity for all persons with disabilities, including persons with psychosocial/mental disabilities." Read more: mindfreedom.org/ campaign-disabilities

In a statement to a session of the United Nations Human Rights Council in Geneva on March 4, 2013, the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment of Punishment called for a "ban on forced psychiatric interventions including forced drugging, shock, psychosurgery, restraint, and seclusion, and for repeal of laws that allow compulsory mental health treatment and deprivation of liberty based on disability, including when it is motivated by 'protection of the person or others.'"

More recently, the United Nations, in relation to World Mental Health Day, issued a strongly worded report calling for a worldwide revolution in mental health. Full report: mindfreedom.org/david-oaks-report

The report was authored and presented by Dr. Dainius Pūras, a professor of psychiatry from Lithuania who was appointed by the United Nations as an independent expert and Special Rapporteur on the right to health. The report was presented to the Human Rights Council in Geneva on October 10, 2018. The report, which can be read in full here: **mindfreedom.org/revolution-mental-health-care**, calls for a radical and global "shift in approach" to the treatment of mental health issues.

> "The urgent need for a shift in approach should prioritize policy innovation at the population level," Puras writes. "Targeting social determinants and abandoning the predominant medical model that seeks to cure individuals by targeting 'disorders.'"

Dr. Pūras calls for a move away from the biomedical model and "excessive use of psychotropic medicine" while laying out the current challenges facing mental health care. The report identifies three major obstacles to reform, including the dominance of the biomedical model, power imbalances, and the biased use of evidence in mental health research.

> "The focus on treating individual conditions inevitably leads to policy arrangements, systems, and services that create narrow, ineffective, and potentially harmful outcomes," he writes. "It paves the way for further medicalization of global mental health, distracting policymakers from addressing the main risk and protective factors affecting mental health for everyone."

NUT

Items for Action

Help Enforce Disability Rights in the US

If you or someone you love has been forced to be in a psychiatric facility such as a state mental hospital, where you/they have been subjected to physical, mental, or sexual abuse, you can file an Americans with Disabilities Act (ADA) complaint, including any complaint alleging Olmstead violations, or disability discrimination against a state or local government, by mail or email.

To learn more about filing an ADA complaint, visit online at: **ada.gov/complaint**. Instructions for submitting attachments are on the form.

To file an ADA complaint by mail or fax:

US Department of Justice
950 Pennsylvania Avenue, NW
Civil Rights Division
Disability Right Section-1425 NYAV
Washington, DC 20530

If you have any questions about filing an ADA complaint, please call: ADA Information Line: **800-514-0301** (voice) or **800-514-0383** (TTY)

Share and Report with David W. Oaks

David Oaks, a psychiatric survivor and human rights activist since 1976, encourages other activists to share this report with their friends on his blog: **mindfreedom.org/un-report-mental-health**

Download, print, and distribute directions for individuals to seek redress for a human rights violation through the United Nations: **mindfreedom.org/directions-seek-redress**

Psychiatric Coercion

Personal Stories Involving Coercion and Psychiatry

"I walked into my psychiatrist's office—it was the end of the day on a Friday and it was pouring rain outside. Last time, he pressured me to step up my dose of antipsychotics but I refused. He also pressured me to go on lithium in addition to the drug I was already on. This time, I told him how I was feeling: fine, just a bit tired at the end of the week and drenched from the rain. He told me that I didn't look very well, and that I should probably consider electroshock therapy because nothing else was working and I wasn't willing to be on other meds. He was making very serious medical decisions based on the fact that I looked tired. He didn't do any diagnostic tests, he didn't even know anything about me or have any longitudinal data on my emotional state. Imagine if a primary care doc told you that you should have brain surgery because he thought you looked tired. It's almost unthinkable. But in psychiatry, that's what happened to me.

I lied and said I would think about it, and then never returned. He made me feel like I was crazy, and like I didn't even know myself. The way he aggressively escalated prescriptions was scary. Today, I'm off all psychiatric drugs, and I feel well. I went to graduate school, and I learned to cope with emotional skills like the ones in the DBT handbook. I'm thankful that I didn't let him determine my treatment, and that I was in a position to say no. Psychiatrists are in an incredible position of power that is easy for them to abuse because there is no system of accountability. It's the psychiatrist's word against yours, and yours is already viewed with skepticism because you are viewed as 'crazy.' It's an incredibly vulnerable and scary position to be in."—Anonymous

"I originally went to see a doctor about an upset stomach. The doctor said I had an anxiety disorder and needed to take medication to treat it. I was given an SSRI to take daily. I felt worse over time. I was then told I had bipolar disorder, an illness that also needed medication to treat it. I was given more psych pills, and each year I felt worse and each time the psychiatrist increased my dose and sometimes added another psych pill. Many of the psych pills had horrible side effects that I could not tolerate. The doctors made me feel like I was the problem, not the pill. One psychiatrist fired me as his patient because I would not take Risperdal. I refused to take it after trying it for one week on the lowest dose because I could barely get out of bed, I could not drive, which I needed to do for my work, and I could barely walk and keep my eyes open.

When I heard that my pills could be creating my problems from other peers, online sources, and books, I decided I wanted to withdraw from the pills. The new psychiatrist was not supportive of my idea. He told me if I was going to stop I could quit taking clonazepam cold turkey. He was wrong; the withdrawal from stopping this pill cold turkey was horrendous for me. He then went on a sabbatical, so I was assigned another psychiatrist. She gave me a tapering schedule, but it was too fast, so I gave a suggested tapering schedule and she said yes, go ahead and do that. It was still too fast and my therapist and doctors did not have the knowledge to know how to support me with all the withdrawal effects I experienced. They all said the effects of lowering the dose and withdrawing from the pills was a sign that I had an illness and encouraged me to go back on the pills. I did not go back on; I made it through the awful withdrawal effects, and I do not have the ups and downs I used to have. The doctors gave me a lot of incorrect information about what was happening with me, how psychiatric pills would affect me, and how to withdraw from them safely."– Anonymous

"At twenty-nine years of age my girlfriend was killed, and I fell into a deep depression. After seeking help for the 'grieving process,' the medical doctors decided I was depressed. I was simply put on Prozac and many other medications for over twenty-five years. During that time police were called one day when the doctor thought I was a threat to myself. The police coerced me into being committed to a lock-down hospital, stating, 'If you do not go voluntarily you will be forced to go.' I complied, which in turn caused my depression to become much worse.

After being placed on a forced three-day hold I was told, 'If you do not comply to ECT you will be placed on another thirty-day hold.' Reluctantly, I complied. Again, my symptoms became much worse because of their coercion. My memory was permanently damaged from ECT as was my CNS. I developed PTSD from this horrific experience. I developed a seizure disorder following my release after ECT. I have been on an SSDI for over twenty-seven years now with all hope of a normal life being long gone."
—Michael Barnes
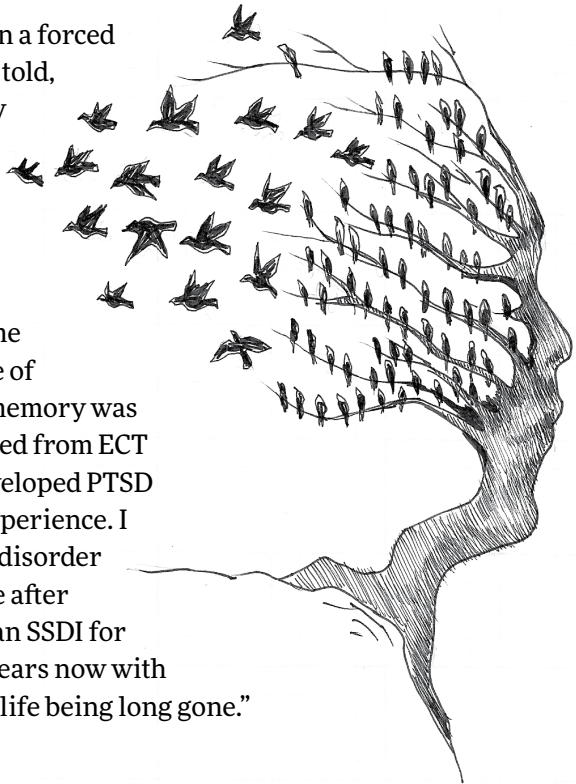
Psychiatric Drugs and Iatrogenic Harm
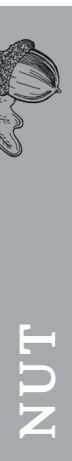
> **"The main reason we take so many drugs is that drug companies don't sell drugs, they sell lies about drugs. This is what makes drugs so different from anything else in life . . . Virtually everything we know about drugs is what the companies have chosen to tell us and our doctors . . ."**
>
> *–Dr. Peter Gøtzsche,*
> author of ***Deadly Medicines and Organised Crime: How Big Pharma Has Corrupted Healthcare***

New research estimates that about one in six American adults take at least one psychiatric drug (mindfreedom.org/one-in-six-psychiatric-drugs). 80 percent of those reported long-term use, which experts say is concerning since many of the drugs are recommended for shorter use and carry a number of serious risks. Read the CBS report: mindfreedom.org/psychiatric-drugs-widespread

The subject of psychiatric drug use is very complex and touches on many issues. This chapter cannot comprehensively cover every one.

This chapter interweaves narratives of psychiatric survivors who identify with having been harmed by psychiatric drugs as well as data from psychiatrists and researchers whose findings support their claims.

The purpose of this information is not to give medical advice but to empower people to have honest conversations with their prescribers about psychiatric drugs, side effects, harm mitigation, and the topic of drug discontinuation and/or reduction.

Neurotoxins Disguised as "Medicine"

Peter Breggin, MD, is a psychiatrist who has spent his entire career researching and documenting harm caused by psychiatric drugs and supporting individuals with mental and emotional issues without the use of psychiatric drugs. His work is cited in this section. He frequently uses the term "neurotoxin" when referring to psychiatric drugs. There is a credible body of evidence to sustain the use of this term.

The term medication or medicine is generally avoided in this handbook unless it is a part of a book title, quote, etc. because it infers that psychiatric drugs are "medicinal" in nature by correcting an abnormal state as with other illnesses.

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Psychiatric Drugs: Correcting an Abnormality?

> "If you walk up to an average person on the streets and ask them what is the cause of bipolar disorder and schizophrenia, I'm sure a lot of them will tell you that it's an incurable condition caused by a chemical imbalance, an imbalance that comes from some kind of faulty genes and something that runs in families. To put it bluntly, the problems are biological in nature and the only thing we can do about them is take meds for life."—Sean Blackwell, watch the video at: mindfreedom.org/bipolar-disorder-lie-video

> "Despite six decades of intensive research in neuropharmacology, there is a lack of evidence that psychiatric drugs have a disease-specific action independent of their demonstrable psychoactive effects. These facts suggest that a radical change of thinking may be necessary about the nature, possibilities, and limitations of psychiatric drug treatment." —Moncrieff, et al., *Journal of Psychoactive Drugs*, mindfreedom.org/psychoactive-effects-meds-elephant

There is no replicable proof that psychiatric drugs correct any known abnormality in the human brain. In fact, there is no underlying proof that mental health disorders are diseases like diabetes or lung cancer, even though that is what many medical professionals routinely tell their

patients. That is why there are zero biologically based procedures in use to confirm psychiatric diagnoses, as with blood or tissue samples, brain scans, etc. with other physical diseases.

> "The only biochemical imbalances in the brains of people who see psychiatrists are the ones put in there by the psychiatrists. We don't have any evidence that any routine psychiatric problem from anxiety, to depression, even schizophrenia has anything to do with a biochemical imbalance." Source: *Do You Have a Biochemical Imbalance?* Dr. Breggin's Simple Truths video: youtu.be/ARZ2Wv2BoFs

Dr. Moncrieff, a psychiatrist and researcher in the UK, argues that psychiatric drugs cannot be proven to reverse any known disease, so the wide-scale use of psychiatric drugs in the practice of psychiatry to "cure" or manage diseases as with other conditions such as diabetes is demonstrably false and disingenuous. She argues that psychiatry should adopt a more honest "drug based" model:

> "In contrast, the 'drug-centered' model suggests that far from correcting an abnormal state, as the disease model suggests, psychiatric drugs induce an abnormal or altered state. Psychiatric drugs are psychoactive substances, like alcohol and heroin. Psychoactive substances modify the way the brain functions and by doing so produce alterations in thinking, feeling, and behavior. Psychoactive drugs exert their effects in anyone who takes them regardless of whether or not they have a mental condition. Different psychoactive substances produce different effects, however. The drug-centered model suggests that the psychoactive effects produced by some drugs can be useful therapeutically in some situations."

Dr. Moncrieff explains how adoption of a drug-based approach would give far more weight to the subjective experience of prescribed drugs as reported by those who take them. Those who like the experience could continue to take them as desired, while those who have a negative experience would not be assumed to lack insight, which is the justification for drugging by force.

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"If someone experiences relief from a headache by taking an aspirin, we wouldn't say that person is suffering from an aspirin deficiency."

–Anonymous

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In the 1950s researchers searching for a cure for tuberculosis gave an experimental substance to severely ill patients, hoping it would cure their tuberculosis. While it failed to cure the patients, the researchers observed that this mysterious substance had a sedating effect on them. They named the substance Thorazine and aggressively marketed it to mental hospitals even before its mechanism of action (dopamine blockage) was understood. Later, as more became known about the role of neurotransmitters in the brain, an abnormality was postulated to fit the drug. This marked an important departure from good medical science:

> "Because Thorazine was found to lower dopamine levels in the brain, it was postulated that psychoses like schizophrenia are caused by too much dopamine. Or later, because certain antidepressants increase levels of the neurotransmitter serotonin in the brain, it was postulated that depression is caused by too little serotonin . . . Thus, instead of developing a drug to treat an abnormality, an abnormality was postulated to fit a drug.

> By this same logic one could argue that the cause of all pain conditions is a deficiency of opiates, since narcotic pain medications activate opiate receptors in the brain. Or similarly, one could argue that fevers are caused by too little aspirin."
> —Marcia Angell, *New York Times* Review of Books: mindfreedom.org/why-epidemic-mental-illness

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Thorazine ignited a pharmacological gold rush and set the stage for all future psychiatric drug research. From that point on, the merits of every new psychiatric drug would be based on its performance in hastily arranged, short-term drug trials. There would be little interest in long-term controlled studies in the heady rush to get new drugs to market. There was little interest in the new drug's long-term safety or pursuing other more promising nonpharmacological treatment options that would prove to be less harmful.

According to researchers Jeffrey Lacasse and Jonathan Leo, psychiatric drugs are aggressively marketed to consumers using false and misleading claims:

"In the United States, selective serotonin reuptake inhibitor (SSRI) antidepressants are advertised directly to consumers[1]. These highly successful direct-to-consumer advertising (DTCA) campaigns have largely revolved around the claim that SSRIs correct a chemical imbalance caused by a lack of serotonin (see Tables 1 and 2 at mindfreedom.org/serotonin-depression-disconnect). For instance, sertraline (Zoloft) was the sixth best-selling medication in the US in 2004.

Contemporary neuroscience research has failed to confirm any serotonergic lesion in any mental disorder, and has in fact provided significant counter evidence to the explanation of a simple neurotransmitter deficiency. Modern neuroscience has instead shown that the brain is vastly complex and poorly understood."[2] —Jeffrey Lacasse, Jonathan Leo, *PLOS Medicine,* mindfreedom.org/serotonin-depression-disconnect

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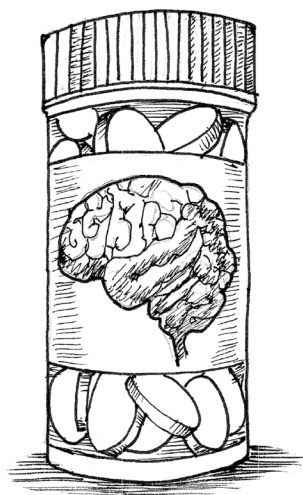
1   B Mintzes, title in italics (BMJ, 2002), 324: 908-909..
2   J Horgan, title in italics (New York: Free Press, 1999), 336..

> **"I spent several months taking a very powerful 'antipsychotic' tranquilizer drug called Navane, used to treat schizophrenia. It completely changed my personality and denied me the most basic sense of who I was; it made me stupider, slower, fatter, and also, because of the side effects, at times more desperate and suicidal."**
>
> *–Will Hall*
> mindfreedom.org/will-hall

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Psychiatric Drugs and Choice

Today, one out of four Americans take at least one prescribed, psychiatric drug. The majority of people who take psychiatric drugs do so voluntarily.

Individuals who voluntarily take psychiatric drugs are exercising their right to choose, a right supported by many psychiatric rights/survivor organizations such as MindFreedom International.

Some people who choose to take psychiatric drugs or who make that decision for someone else may not even be aware that effective nondrug alternatives exist. They may not be aware that a growing number of experts believe nondrug alternatives are safer and result in better long-term outcomes.

Grace Jackson, MD, argues in her book ***Rethinking Psychiatric Drugs: Guide for Informed Consent*** that the standard for informed consent is very low.

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If the standard for informed consent (involving people who take drugs voluntarily) is too low, what does that say about the standard needed to forcibly administer psychiatric drugs to people?

> "Debate surrounding assisted outpatient treatment has mostly focused on issues of due process, cost-effectiveness, and efficacy as measured by readmission and incarceration rates. Less attention has been paid to whether long-term use of antipsychotic treatment is supported by sufficient evidence to warrant its compulsory use in assisted outpatient treatment programs."—Shawn S. Barnes mindfreedom.org/shawn-barnes

It is imperative that policy makers, caregivers, lawmakers, and treatment providers who administer psychiatric drugs by force listen to the stories of psychiatric survivors. These stories are notably absent from medical journals and hearings in which mental health policies are discussed.

"At age twenty-six, I hit a breaking point, and wandered the streets of San Francisco all night hearing angry voices telling me to kill myself. I ended up in the locked unit of the public psychiatric ward in San Francisco. I was never asked if I wanted to go to the hospital, or given options or support in figuring out what to do. I was just observed for several hours in a clinic, and then they announced that I couldn't leave. I was told I was

a danger to myself and that it was for my own good, but like so many people it was really being in the wrong place at the wrong time. I begged them not to lock me up, because I didn't want to lose my two jobs. I kept saying please let me go so I can go to work, please, I can make a no harm contract, I don't want to miss work. But I ended up losing those jobs. When I arrived at the hospital, it was like a prison. The chaos and violence, the crowding and screams were terrifying. Throughout the night police brought in anyone fitting the 'mental' description and dumped us all together. In my vulnerable and fragile emotional state the impact of this pandemonium was devastating. I was in shock from fear.

That began a year-long stay in the public mental health system. I needed help, but instead I was treated like a disobedient child with a broken brain, punished and controlled, and given more than two months in a locked unit. I went from being a human being to being a mental patient. I was put in restraints— not because of anything I did but they said it was just for transporting me to the hospital. After being restrained I had nightmares that I was being raped, and I still have flashback reactions to anything that reminds me of that experience. During the time I was in the system I was locked in an isolation cell, threatened with being strip-searched, given more than a dozen different drugs, and subjected to patronizing group therapy that never acknowledged what was really going on.

At one residential facility I was at, a man had killed himself right before I arrived. A patient who was his friend told me why: he was having severe side effects from his meds and no one was listening to him. The meds were why he jumped off the roof and killed himself, not mental illness. When I was on medication it was impossible to know how much of my pain was the medication, not the problems I had to begin with. I have photos of that time, and the look in my eyes is totally different,

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not me, a different person. I was basically a zombie, but I was being docile so they considered it recovery. Today I worry that I might have some lingering side effects from the Navane and other drugs I took, including twitching in my body, memory disturbances, and worsened panic. There could be other long-term damage that I may never be able to sort out and recognize.

My father is a Korea War veteran and an electroshock survivor from hospitalizations in the 40s and 50s; he was subjected to what amounts to torture by doctors, at the request of my grandfather to punish him for acting out as an adolescent. My father's emotional scars from this directly affected me and the rest of my family, because he never got adequate help and carried around severe trauma all during my childhood. When my own psychiatrists found out that my father had been in mental hospitals too, they used this to try to convince me my problems were genetic brain malfunctions correctable by medications. Not once did they ever ask me about my own childhood experiences of trauma, or make the connection of how this might be behind my difficulties. Only later, after researching things on my own and discovering the writing of Robert Whitaker and others, did I learn that there is no solid science behind blaming genetic predispositions and chemical imbalances, and that childhood trauma can play a big role in what gets labeled as 'mental illness.'"—Will Hall, educator, psychiatric survivor/activist, therapist, cofounder of the Freedom Center and *Madness Radio.*

"Angrily they would tell her to 'get up' and not act like that, as if she had some choice in the matter!"
*–Jim Maddock*

"So we were admitted to the clean, brightly lit modern GF wing where I recall signing some admission papers. At that stage, I still had faith in the system, not liking it but thinking there were no alternatives. But if there were improvements in the hospital environment, the treatment being offered was still the same, namely experimentation with different tablets to try to counter a 'chemical imbalance in the brain.' So Mary, like all the other patients, was given medication to 'bring her down.' I don't remember there being too much by way of 'talk therapy' and while there was some occupational therapy in an added-on prefab building that seemed to be something of an afterthought, the 'medical model' was the predominant treatment on offer. Because the professional 'experts' said so and because, as a layman, I trusted them, I went along with them. Drug treatment was the only way. Any possible negative side effects were played down or brushed aside. The main thing was to find the right drug and to right the 'chemical imbalance.'

I didn't know then what I know today. There can be a whole range of the most awful side effects to all medications, ranging from suicidal thoughts to hallucinations to other serious physical consequences. When these manifest themselves, they are considered to be part of the psychiatric 'condition' to be treated with even more medication in a misguided and vicious cycle. On a number of occasions, Mary was overcome by a faint-like weakness that caused her to fall to the ground. The reaction of the nurses, whenever this happened, showed how ignorant they were of these side effects. Angrily, they would tell her to 'get up' and not to act like that, as if she had some choice

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in the matter! On top of that, they would make threats to her that she would not be allowed visitors–emotional blackmail of an emotionally disturbed patient–completely at odds with the best traditions of their profession."—Jim Maddock, describing Mary's second hospitalization in *Soul Survivor: A Personal Encounter with Psychiatry* by Mary and Jim Maddock
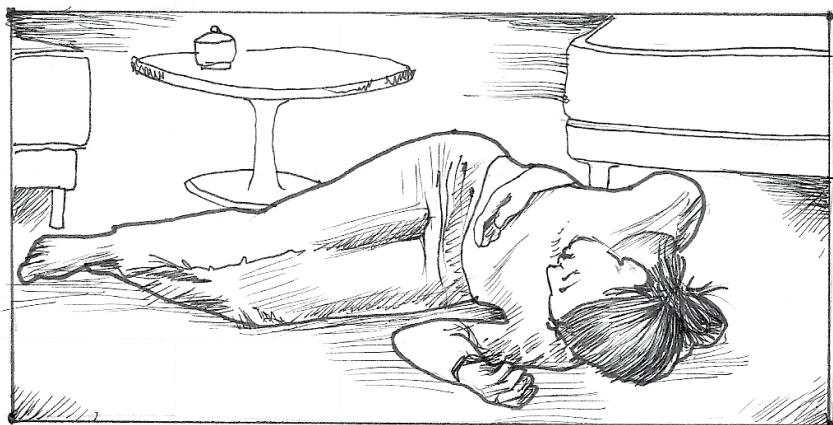
"I have estimated, based on randomized trials and cohort studies, that psychiatric drugs kill more than half a million people every year among those aged sixty-five and above in the USA and Europe. This makes psychiatric drugs the third leading cause of death, after heart disease and cancer. The drugs furthermore cripple tens of millions. There are no benefits that can justify so much harm."—Peter Gøtzsche, MD, former director of The Nordic Cochrane Centre

Drug Side Effects

> **"These drugs have so many side effects because using them to treat a complex psychiatric disorder is a bit like trying to change your engine oil by opening a can and pouring it all over the engine block. Some of it will dribble into the right place, but a lot of it will do more harm than good."**
>
> *–David Anderson, neurobiologist*

"Full Disclosure Needed About Psychiatric Drugs that Shorten Lives," by Paula Caplan, *Psychology Today*: mindfreedom.org/full-disclosure-needed

"12 percent of adults reported using long-term antidepressants," CBS NEWS REPORT: mindfreedom.org/psychiatric-drugs-widespread

"Psychiatric Drugs Kill More Americans than Heroine," by Kenneth Anderson, Pro Talk: mindfreedom.org/psych-drugs-kill-heroin

> **"All drugs have side effects, but people often don't link the effect they are experiencing to starting, stopping, or changing the dose of a drug."**
>
> *–Rxisk: Making Medicines Safer For All of Us*
> rxisk.org

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According to Wikipedia, **akathisia** (mindfreedom.org/wikipedia-akathisia), a movement disorder characterized by a feeling of inner restlessness and inability to stay still, is another serious side effect experienced by one-third of individuals who take neuroleptics. It is also known to affect people who take antidepressants.

Symptoms of akathisia may vary from a mild sense of disquiet or **anxiety** (mindfreedom.org/wikipedia-anxiety) to a sense of terror. People typically pace for hours because the pressure on the knees reduces the discomfort somewhat; once their knees and legs become fatigued they sit or lie down, although this does not relieve the akathisia.

When misdiagnosis occurs in neuroleptic-induced akathisia, more antipsychotics may be prescribed, potentially worsening the symptoms. Psychologist Dennis Staker had drug-induced akathisia for two days. His description of his experience was this: "It was the worst feeling I have ever had in my entire life. I wouldn't wish it on my worst enemy."

Jack Henry Abbott describes akathisia as:

> " . . . [It comes] from so deep inside you, you cannot locate the source of the pain . . . The muscles of your jawbone go berserk, so that you bite the inside of your mouth and your jaw locks and the pain throbs . . . Your spinal column stiffens so that you can hardly move your head or your neck and sometimes your back bends like a bow and you cannot stand up . . . You ache with restlessness, so you feel you have to walk, to pace. And then as soon as you start pacing, the opposite occurs to you; you must sit and rest. Back and forth, up and down you go . . . you cannot get relief . . . "

Many patients with akathisia describe symptoms of neuropathic pain akin to fibromyalgia and restless leg syndrome. Dr. David Healy defines akathisia as insomnia, a sense of discomfort, motor restlessness, and marked anxiety, panic, and weepiness. More worrisome is the potential link between akathisia and suicide, aggression, hostility, and even homicide.

Stories involving antidepressant use and suicide are common. See example: **mindfreedom.org/ssri-induced-suicide**. The FDA, unable to ignore hundreds of such stories, ordered drug manufacturers to add "suicidality" as a black box warning on many antidepressants marketed in the US starting in the late 90s.

Two researchers offer this theory to explain why antidepressants raise the risk of suicide for some people: **mindfreedom.org/neurotrophin-theory-case-study8**

Many experts believe that there is a strong link between psychiatric drug use and violent crime, including school shootings. The International Society for Ethical Psychology and Psychiatry created a white paper summarizing the evidence for a link between violence and psychiatric drugs in general: **mindfreedom.org/white-paper-psychiatric-drugs-violence**

In an article in the *Journal of Forensic and Legal Medicine* the link between cytochrome P450, neuroleptic/antidepressant-induced toxicity, and crime is described: **mindfreedom.org/cytochrome-akathisia-violence**

Although the link between antidepressant use and increased risk of suicide is well established, very little research has been conducted to explain this. Some researchers believe that answers may lie in genetic variance. As the researchers explain, many people, due to a genetic variance, lack the liver enzymes to properly detoxify/metabolize psychiatric drugs when prescribed in normal dosage ranges.

Many patients are afraid to confide in their doctor when they experience side effects from psychiatric drugs. If you feel you are suffering from side effects, visit **Rxisk.org** and request a free report based on your profile.

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Twenty Reasons to Be Concerned By Antidepressants

Antidepressants can cause:

1. Depression
2. Mania and psychosis
3. Suicidality
4. Violence
5. Cancer
6. Damage to babies during pregnancy, including an increased risk of autism
7. Damage to brain cells
8. Weakening of bones
9. Increased risk of diabetes
10. Uncontrollable body movements
11. Increased risk of stroke
12. Increased risk for dementia
13. Restlessness, nervousness, and insomnia
14. Cell death
15. Ongoing weight problems, even after stopping
16. Apathy and memory impairment
17. Sexual problems that may continue even when the drugs stop
18. Early mortality
19. Loss in brain's ability to self-regulate
20. Serious addiction and terrible withdrawal symptoms

Full text plus citations can be found at:
mindfreedom.org/mythsandrisks

Reasons to Be Concerned About Neuroleptics

1.6 percent of Americans reported taking neuroleptics.–CBS NEWS

Neuroleptics, also known as "antipsychotics," are associated with goiter, diabetes, heart disease, and metabolic disorder. They are known to cause cognitive impairment such as difficulty focusing, thinking, and remembering. Most notably they cause extreme fatigue. It is not uncommon for people on neuroleptics to sleep sixteen hours daily, making it difficult for them to engage in employment and daily life activities.

Neuroleptics also cause what is known as "negative symptoms" or extreme social withdrawal, making it difficult to maintain relationships with family and friends.

One side effect includes tardive dyskinesia (TD), a disorder characterized by involuntary movements most often affecting the mouth, lips, and tongue, and sometimes the trunk or other parts of the body such as arms and legs. Taking these drugs over a long period of time—usually many years—increases the risk of long-term side effects.

Study reveals how many US adults are taking psychiatric drugs:
mindfreedom.org/psychiatric-drugs-widespread

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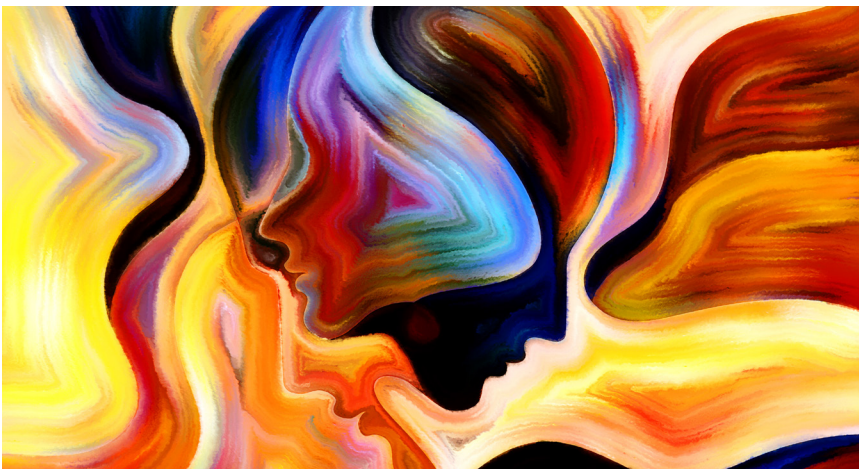
> **"There is a lopsided relationship between vulnerable patients and their doctors who have extraordinary power and knowledge over them . . . The systems and organizations we all rely on to keep us safe are fundamentally broken."**
> *–rxisk.org*

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RxISK

RxISK is run by a group of medical experts with international reputations in early drug side-effect detection and risk mitigation, pharmacovigilance, and patient-centered care. Their website says the following about drug side effects:

· Drug side effects are a leading cause of death in hospitals and may be the leading cause of death outside hospitals.

· 100 percent of patients suffer unintended effects from their prescriptions.

· The annual cost of drug side effects is estimated to be considerably more than $100 billion, yet comprehensive, relevant data necessary to manage a solution is not collected.

· More than 95 percent of drug side effects go unreported, and there are serious gaps and delays in getting relevant feedback on effects of pharmaceuticals once they are released to the market.

· Regulators do not have reporting systems geared to capturing the data needed for effective post-market monitoring.

"Medication spellbinding in technical language is intoxication anosognosia."

–Peter Breggin, MD

Dr. Peter Breggin, author of **Medication Madness**, describes the inability of many people to consciously realize how psychiatric drugs are affecting them. He has provided expert testimony in many criminal trials involving people who have committed bizarre criminal acts while intoxicated by psychiatric drugs. He calls this phenomenon "medication spellbinding."

DR. PETER BREGGIN

For this reason it is imperative that psychiatrists inform their patients about the potential for psychiatric drugs to cause new psychiatric symptoms and monitor their patients carefully.

Dr. Breggin also describes how psychiatric drugs cause drug-induced psychiatric Chronic Brain Impairment:

> "Every type of psychiatric medication initially produces effects that are specific to the particular drug's unique impact on neurotransmitters and other aspects of brain function. For example, the SSRI antidepressants block the removal of the neurotransmitter serotonin from the synapses; the antipsychotic drugs suppress and block dopamine neurotransmission; and the benzodiazepines amplify GABA neurotransmission which in turns suppresses overall brain function. Although all psychiatric drugs have specific initial biochemical effects, over time other neurotransmitter systems react to the initial effects and broader changes begin to take place in the brain and in mental functioning."

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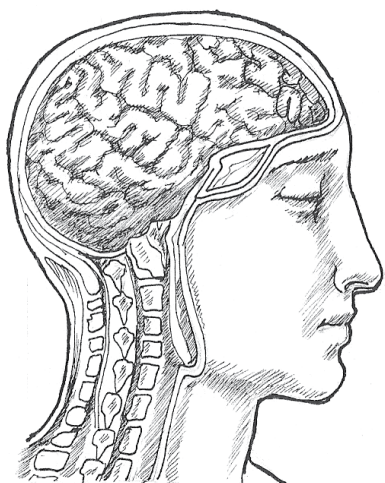
> **"Biopsychiatry has become increasingly fond of blaming the patient."**
>
> *–Dr. Grace Jackson*

When drug treatment fails, patients are blamed, especially if that treatment leaves them worse off than before. Prescribers are trained to use a simple prescription "algorithm" developed by drug companies. When a highly touted prescribed drug fails to help a patient, the algorithm is consulted to identify alternative treatments. If a patient "fails" two or more "treatments" they are said to be "treatment resistant."

Failure to Inform Patients

Patients are routinely informed that they must stay on the drugs for life, just like people with diabetes must take insulin, despite the lack of evidence that they have any known abnormality in their brain, such as a chemical imbalance.

They are also not informed about the data showing that people who stay on antidepressants do worse in the long run than people who choose nondrug alternatives: mindfreedom.org/antidepressant-worse-long-term. The data shown at: mindfreedom.org/antipsychotics-worsen-schizophrenia strongly suggests the same for people on "antipsychotics."

Polypharmacy

Many prescribers who believe a drug has failed augment it with yet another drug. This is known as polypharmacy. Polypharmacy can increase the risk of toxic drug interactions and lower quality of life. More details about polypharmacy can be found by reading this paper: mindfreedom.org/polypharmacy-caution

Patient factors associated with polypharmacy include:

- · A higher degree of disability (i.e. sicker patients)
- · Repeat hospitalizations within one year
- · Younger age
- · Being male
- · Detention on an involuntary commitment
- · A diagnosis of schizophrenia, bipolar disorder, or mania

The Food and Drug Administration has never tested the safety of drugs in combination. Polypharmacy can make it more difficult for patients and doctors to pinpoint and resolve life-threatening side effects.

The risks related to polypharmacy involving young people are starting to get attention from mainstream corporate media: **mindfreedom.org/kids-multiple-drugs**

Often secondary drugs are prescribed to deal with side effects from the original drugs such as incontinence, thyroid problems, diabetes, tardive dyskinesia, and others.

Many psychiatric survivors claim that as their drug intake increased, they became sicker and sicker. It is not uncommon for psychiatric patients to be on as many as ten drugs at a time!

Drug failure also presents itself in the form of drug intolerance, whereby a person must receive higher and higher dosages to get the same effect. This is another pathway to polypharmacy. Many prescribers, when the maximum recommended dosage of one drug has been reached and the desired outcome is still not achieved, bypass limits by augmenting the

first drug with yet another drug. This masks a drug's ineffectiveness and increases the risks of side effects.

Paradoxical Reactions

A paradoxical reaction is a type of adverse drug reaction that may happen very quickly with the introduction of a new psychiatric drug. Paradoxical symptoms can have life-altering, even deadly effects.

Paradoxical reactions involve new symptoms a patient has never experienced prior to the introduction of a new drug or the worsening of existing symptoms.

Paradoxical symptoms can include agitation, impulsivity, disinhibition, akathisia, psychosis, hostility, violence, aggression, suicidality, dissociation, and depersonalization. These are behaviors which can lead to loss of employment, permanent loss of relationships, and even criminality!

Adverse or paradoxical drug reactions are well documented by the FDA, and most antidepressants and neuroleptics (marketed as antipsychotics) have black box warnings with detailed lists of unusual behaviors that can be drug related.

Many patients may not understand that they are experiencing paradoxical drug reactions, and their doctors often don't recognize and/or report them.

When Drugs Cause Psychiatric Symptoms

> **"More than one-third of American adults take medications that have the potential to cause depression."**
> *–Lisa Rapaport, Reuters*

mindfreedom.org/depression-adults-medicine

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Psychiatric drugs can cause people to lose touch with reality. In 2011, an emergency room doctor sought emergency medical treatment while experiencing an adverse reaction. She was diagnosed as having bipolar disorder with psychosis by the resident psychiatrist who immediately took actions to have her medical license revoked. After her condition was correctly attributed to a prescription medication for asthma and was resolved, her license was reinstated and she is now suing the psychiatrist who mistook her adverse drug reaction for a preexisting mental health disorder. Read the full article: mindfreedom.org/er-doctor-sues

One can only wonder how many individuals who are experiencing an adverse drug event end up locked up and forcibly medicated. Many do not possess the considerable resources possessed by the doctor in the story described here.

It is important for people with modest resources to prevent psychiatrists from exercising unchecked power. One way to do this is to use "people power." Social media provides new opportunities for people to share individual stories of psychiatric abuse and expose violations of rights. Below are some Facebook groups set up for psychiatric survivors and their family members to network for this purpose:

Legal Death—In Drugs We Trust: facebook.com/Legaldeath

Prescripticide: facebook.com/prescripticide

Experts have noticed a large spike in the number of individuals receiving a bipolar diagnosis after starting prescribed antidepressants.

It is now generally accepted by many experts that a group of drugs called selective serotonin reuptake inhibitors (SSRIs), such as Prozac, induce "hypomania" in many people, leading to a false diagnosis of bipolar.

Well-known psychologist Philip Hickey exposes this disturbing trend with data gleaned from several studies in the article "Antidepressant induced mania," which can be read at: mindfreedom.org/antidepressant-induced-mania

Psychiatric Drug Withdrawal Causes Psychiatric Symptoms

Psychiatric drug withdrawal can also result in new psychiatric symptoms that a person never experienced before. Author and mountain climber Matt Samet shared his nightmarish descent into madness while withdrawing from a class of drugs called benzodiazepines (Xanax, Ativan, etc.) in his book **Death Grip: A Climber's Escape from Benzo Madness** mindfreedom.org/death-grip-madness-book. View Matt's story at: mindfreedom.org/samet-climbing-out

Disabilities, Discrimination, and Communication

Preexisting disabilities and drug-induced cognitive impairments can limit a person's ability to convey factual information about side effects to prescribers.

Caregivers may not recognize adverse drug reactions and fail to report strange behavior to the prescriber, believing it to be a part of their loved one's preexisting mental health diagnosis.

Discrimination in the form of ableism may prevent doctors from recognizing and correctly treating life-threatening conditions.

Iatrogenic Harm, Trust, and Communication

Some individuals may start to lose faith in their psychiatrist's judgement after an adverse drug event. They may conceal new or worsening symptoms to avoid having their diagnosis "upgraded" to a more stigmatizing one or having their dosage increased or augmented with other drugs.

Past psychiatric abuse such as being locked up, restrained, forcibly medicated, or more during a crisis may contribute to a patient's fear of disclosing important information about new symptoms, even if a person believes the new symptoms are treatment induced.

Chronicity in an Era of Psychiatric Drugs

> "It seems that Americans are in the midst of a raging epidemic of mental illness, at least as judged by the increase in the numbers treated for it. The tally of those who are so disabled by mental disorders that they qualify for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) increased nearly two and a half times between 1987 and 2007—from one in 184 Americans to one in seventy-six. For children, the rise is even more startling—a thirty-five-fold increase in the same two decades. Mental illness is now the leading cause of disability in children, well ahead of physical disabilities like cerebral palsy or Down syndrome, for which the federal programs were created."—Marcia Angell, "*The Epidemic of Mental Illness: Why?" New York Times* Review of Book: mindfreedom.org/epidemic-mental-illnesss-why

In 2012, Robert Whitaker, an award-winning journalist, wrote a book ***Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America***. Many activists consider this book to be an important catalyst for the psychiatric survivors movement, just as the publication of Rachel Carson's ***Silent Spring*** catalyzed environmentalists to outlaw DDT.

Originally, Mr. Whitaker's intention was to write a book touting the miraculous new generation of drugs to treat the "severely mentally ill,"

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but what he found while doing research for this book set him on a much different course.

The scientific data did not support the claims by leading "experts" that science, through its discovery and promotion of psychiatric drugs, had made many advances in understanding and treating mental illness. In fact, the opposite was true. The data actually showed a different picture—of deteriorating outcomes and more people becoming chronically ill.

Robert Whitaker, author

The deteriorating outcomes, measured by disability rates (number of individuals on SSI/SSDI), went hand in hand with the rise in the rates of individuals being prescribed psychiatric drugs.

As the former director of medical writing for Harvard University, Whitaker's medical research skills combined with a journalist's curiosity and desire for the truth caused him to tell a much different story. He realized that the media was helping drug companies promote an unfounded "chemical imbalance" theory of mental illness.

The resulting explosion in the number of people taking psychiatric medications, rather than leading to a decrease in mental health related disabilities, actually appeared to be fueling a rise in disability rates.

More importantly, Whitaker pointed out that the media does not encourage audiences to adopt a more nuanced view of psychiatric medications, even though the long-term data strongly suggests that people who avoid long-term psychiatric drug use tend to do better in the long run and enjoy more significant recoveries.

According to a report by the National Center for Health Statistics (NCHS), the rate of antidepressant use in this country among teens and adults (people ages twelve and older) increased by almost 400 percent between 1988–1994 and 2005–2008. Today, one in ten Americans are now taking an antidepressant.

49% of antidepressant studies fail to prove the drugs work[4]

2X Suicide risk for children and young adults up to age 25 if on antidepressants[3]

82% of the benefit of antidepressants is placebo effect[2]

55% of people have withdrawal symptoms when getting off of antidepressants[5]

2-4X greater risk of developing mania if on antidepressants[1]

Antidepressant *Risks & Limitations*

60% of people on antidepressants feel emotionally numb[5]

62% of people on antidepressants experience sexual dysfunction[5]

54% of depressive symptoms remain after taking antidepressants[6]
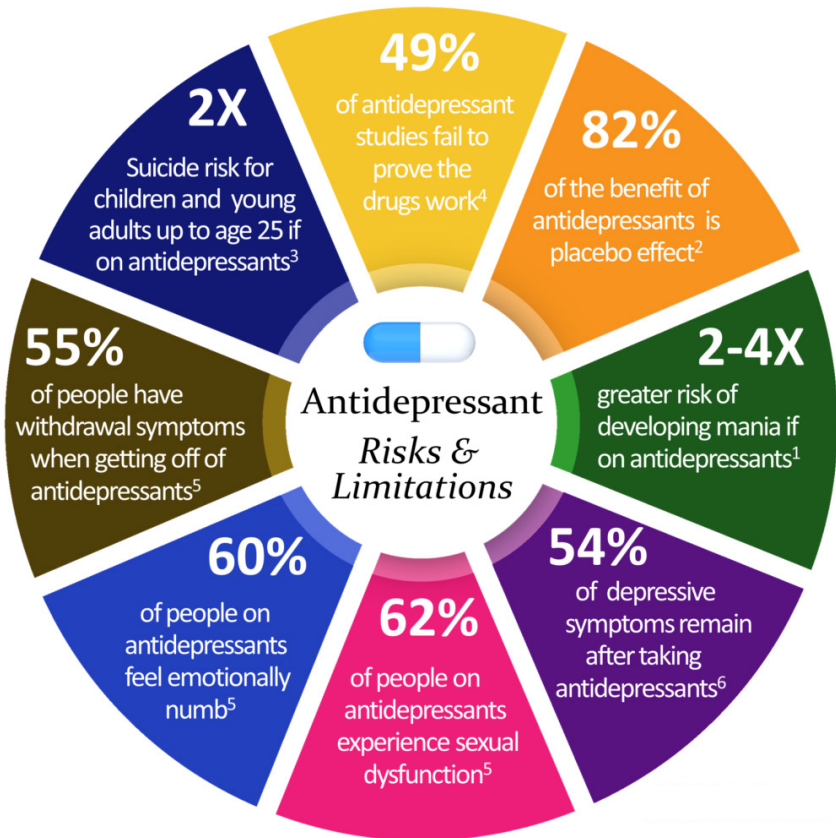
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Illustration: ©2018 Craig Wagner
OnwardMentalHealth.com

"**In 2004 the FDA began at last to acknowledge some of the more devastating effects of psychiatric drugs, including its recent confirmation that antidepressants cause increased suicidality.**"

–Dr. Peter Breggin

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There is **scant evidence, mindfreedom.org/serotonin-depression-disconnect**, that "low serotonin" (chemical imbalance) causes depression. Antidepressants perform so poorly in relation to placebos **that the results are not "clinically significant"** (**mindfreedom.org/moncrieff-and-kirsch-article**), according to Moncrieff and Kirsch. The largest study ever performed on antidepressants shows dismal results in terms of effectiveness (**mindfreedom.org/world-largest-antidepressant-study**.) One researcher discusses how antidepressants have taken on a mythological stature in "Effectiveness of antidepressants: an evidence myth constructed from a thousand randomized trials?" which can be read here: **mindfreedom.org/antidepressants-evidence-myth**

Antidepressants are known to cause side effects ranging from sexual dysfunction to permanent dysphoria. Individuals attempting to withdraw may experience protracted acute withdrawal syndrome (PAWS) and a host of problems involving the nervous system.

Whitaker also describes a chronic form of antidepressant-induced depression called "tardive dysphoria" experienced by those whom have been treated with antidepressants for long periods. Read more at: **mindfreedom.org/tardive-dysphoria-antidepressants**

A drug may provide short-term relief—a phenomenon which many researchers relate to the "placebo effect"—but the benefits may begin to wear off. Psychiatrists often respond by increasing the dosage (which may put people at greater risk of side effects), augmenting ineffective drugs with additional drugs (polypharmacy), or switching or discontinuing/reducing dosages too rapidly (putting people at risk of adverse withdrawal effects).

In this way, prescribers appear to be unaware of the potential for psychiatric drugs to change the structure of the brain.

Antipsychotics

The class of drugs known as "antipsychotics" are generally referred to as neuroleptics in this handbook since the term antipsychotic is a marketing term created by drug companies, and they do not correct any known abnormality in the brain.

Neuroleptics are tranquilizers. One of the most common types of neuroleptics—the new generation of antipsychotics that includes Risperdal, Zyprexa, and Seroquel—works by blocking a neurotransmitter called dopamine at the site where synapses take place in the brain.
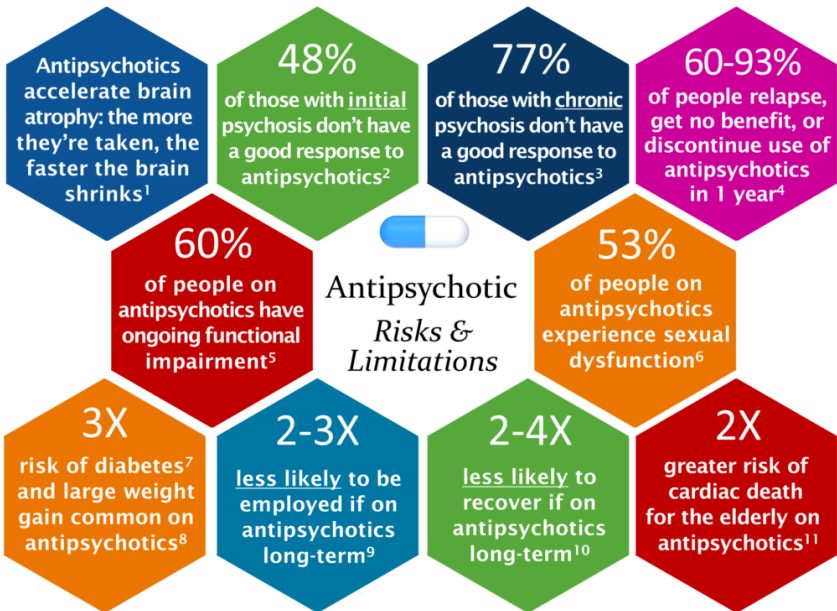
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Antipsychotics accelerate brain atrophy: the more they're taken, the faster the brain shrinks[1]

48% of those with <u>initial</u> psychosis don't have a good response to antipsychotics[2]

77% of those with <u>chronic</u> psychosis don't have a good response to antipsychotics[3]

60-93% of people relapse, get no benefit, or discontinue use of antipsychotics in 1 year[4]

60% of people on antipsychotics have ongoing functional impairment[5]

Antipsychotic *Risks & Limitations*

53% of people on antipsychotics experience sexual dysfunction[6]

3X risk of diabetes[7] and large weight gain common on antipsychotics[8]

2-3X <u>less likely</u> to be employed if on antipsychotics long-term[9]

2-4X <u>less likely</u> to recover if on antipsychotics long-term[10]

2X greater risk of cardiac death for the elderly on antipsychotics[11]

Illustration: ©2018 Craig Wagner, OnwardMentalHealth.com

"In 1994, Harvard Medical School researchers reported that outcomes for schizophrenia patients in the US had declined since the 1970s to the point that they were no better than they had been in 1900. Although the researchers did not blame antipsychotics for the poor outcomes, it is notable that this decline occurred during a period when American psychiatrists began telling the public that people diagnosed with schizophrenia had to stay on the drugs for life. In other words, the decline coincided with the adoption of a paradigm of care that emphasized lifelong drug therapy."—Robert Whitaker
mindfreedom.org/robert-whitaker-antipsychotic

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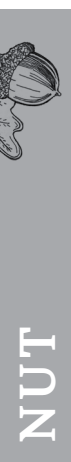
> **"Antipsychotics are not the innocuous substances that they have frequently been portrayed as. We still have no conclusive evidence that the disorders labeled as schizophrenia or psychosis are associated with any underlying abnormalities of the brain, but we do have strong evidence that the drugs we use to treat these conditions cause brain changes."**
>
> *–Joanna Moncrieff*

"Evidence that antipsychotics cause brain shrinkage has been accumulating over the last few years but the psychiatric research establishment is finding its own results difficult to swallow."—Joanna Moncrieff, *"Antipsychotics and brain shrinkage: an update"*

"In 2011, these researchers, led by the former editor of the American Journal of Psychiatry, Nancy Andreasen, reported follow up data for their study of 211 patients diagnosed for the first time with an episode of 'schizophrenia.' They found a strong correlation between the level of antipsychotic treatment someone had taken over the course of the follow-up period, and the amount of shrinkage of brain matter as measured by repeated MRI scans. The group concluded that 'antipsychotics have a subtle but measurable influence on brain tissue loss.'"—Joanna Moncrieff, *"Antipsychotics and brain shrinkage: an update"* mindfreedom.org/moncrieff-brain-shrinkage-antipsychotics

Supersensitivity Psychosis Caused by Neuroleptics

In his book, ***Anatomy of an Epidemic,*** Mr. Whitaker presented evidence that the practice of maintaining people on neuroleptics for long periods in response to what is typically known as a "psychotic episode" appeared to make people more vulnerable to psychosis in the long run and decrease their chances of making a full recovery.

Whitaker describes this phenomenon as "supersensitivity psychosis":

> "In the late 1970s, two physicians at McGill University, Guy Chouinard and Barry Jones, stepped forward with a biological explanation for why the drugs made schizophrenia patients more biologically vulnerable to psychosis. Their understanding arose, in large part, from the investigations into the dopamine hypothesis of schizophrenia, which had detailed how the drugs perturbed this neurotransmitter system. In an effort to compensate for this blockade, the postsynaptic neurons increase the density of their D (two) receptors by 30 percent or more. The brain is now 'supersensitive' to dopamine, Chouinard and Jones explained, and this neurotransmitter is thought to be a mediator of psychosis. 'Neuroleptics can produce a dopamine super sensitivity that leads to both dyskinetic and psychotic symptoms,' they wrote. 'An implication is that the tendency toward psychotic relapse in a patient who has developed such a super sensitivity is determined by more than just the normal course of the illness.
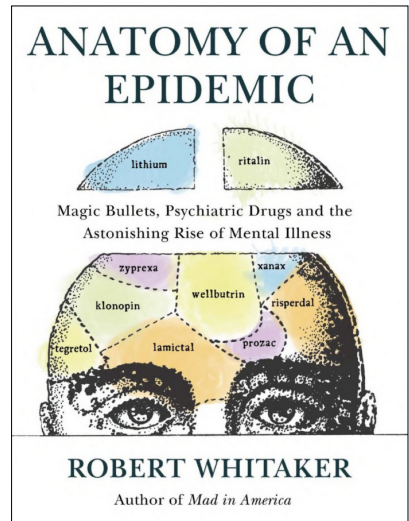
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A simple metaphor can help us better understand this drug-induced biological vulnerability to psychosis and why it flares up when the drug is withdrawn. Neuroleptics put a brake on dopamine transmission, and in response the brain puts down the dopamine accelerator (the extra D two receptors). If the drug is abruptly withdrawn, the brake on dopamine is suddenly released while the accelerator is still pressed to the floor. The system is now wildly out of balance, and just as a car might careen out of control, so too the dopaminergic pathways in the brain. The dopaminergic neurons in the basal ganglia may fire so rapidly that the patient withdrawing from the drugs suffers weird tics, agitation, and other motor abnormalities. The same out-of-control firing is happening with the dopaminergic pathway to the limbic region, and that may lead to 'psychotic relapse or deterioration,' Chouinard and Jones wrote."

Items for Action

· Read ***Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America*** by Robert Whitaker. To order a copy, visit **madmarket.org** or email **office@mindfreedom.org**

· Download, print, and distribute a free information sheet on neuroleptics (available in German, Arabian, English, French, Polish, Romanian, Russian, Serbocroatian, Spanish, and Turkish language) at **mindfreedom.org/neuroleptics-fact-sheet** by Peter Lehmann, Volkmar Aderhold, and other leading psychiatrists

Psychiatric Drug Withdrawal
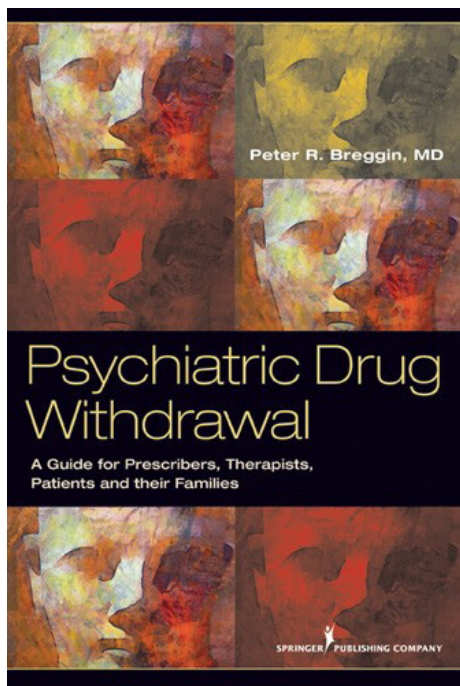
One of the most disheartening things about many mental health providers is their failure to validate unbearable, debilitating side effects and difficulty many of their patients experience when attempting to discontinue or reduce psychiatric drugs. They are not open to the very real possibility that profound structural changes to the brain can occur with prolonged psychiatric drug use.

Many of the resources listed here are from the collective wisdom of people who have successfully discontinued psychiatric drug use.

Disclaimer: *This information is not intended to replace medical advice. Psychiatric drug discontinuation/reduction is a personal decision that is best made in conjunction with a medical professional.*

It is our hope that readers will use this information to start a dialogue with their prescribers and loved ones and make more informed medical decisions, including the decision whether or not to discontinue psychiatric drugs that may be doing more harm than good.

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Benzodiazepine Withdrawal

Benzodiazepines anecdotally are one of the most difficult classes of drugs to discontinue. This drug category includes Ativan, Xanax, Klonopin, etc.

Resources:
Benzodiazepine Information Coalition—education and awareness: benzoinfo.com

Benzobuddies.org—support for those suffering with BWS or tapering off benzos: benzobuddies.org

The Ashton Manual—how to taper off benzodiazepines: benzo.org.uk/manual

Education and a list of some things to avoid during BWS: mindfreedom.org/five-facts-benzo-withdrawal

Drug Habituation
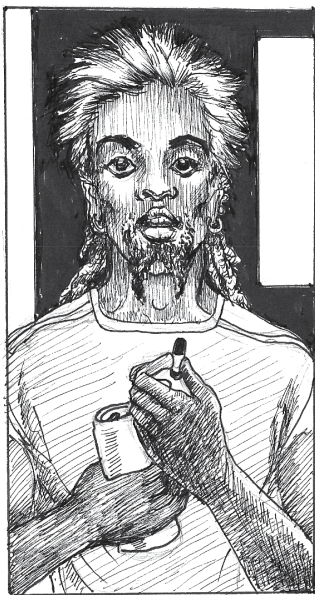
Some individuals start taking psychiatric drugs voluntarily for relief during a crisis. When the crisis is over, they discover that they have become habituated to one or more drugs. This is evident when they attempt to discontinue the drug(s) only to find that the withdrawal symptoms are worse than the symptoms that led them to start taking drugs in the first place.

Individuals who experience prolonged withdrawal symptoms may find that their experiences are not validated by prescribers. They may be told that their withdrawal difficulties are all in their imagination or that their symptoms are related to their "original" illness coming back. They may find it next to impossible to obtain social, emotional, and economic support while withdrawing from one or more drugs.

Activists are calling for psychiatric discontinuation/reduction research and greater opportunities and supports for individuals who want to discontinue/reduce psychiatric drug use. Some are taking matters into their own hands.

Chaya Grossberg exemplifies a trend of survivors assisting one another to heal in the absence of help from within the "system." She observes the difference between people for whom psychiatric drugs appear to "work" and those for whom psychiatric drugs appear to trigger a downward spiral of poor, physical health:

> "For those with very strong kidney/adrenal, liver, digestive, and other organ function, the stress of psychiatric pharmaceuticals can be fielded for quite some time before fatigue sets in. Maybe these folks can take psychiatric drugs for many years and still work at a job, maintain relationships, and keep a solid sleep schedule and basic motivation. These are often the people who find the drugs to 'work.' Their bodies are able to easily release the toxins and continue functioning all right.

> But for those who already have any kidney/adrenal, liver, digestive, or other organ weakness, damage or dysfunction, it is another story. The psychiatric chemicals do not detox easily, the kidneys and adrenals are further weakened by the stress of having to work so hard to detoxify them, and the digestive system is vulnerable to getting sluggish." Read the full article: **mindfreedom.org/mainstream-psychiatry-ableist-article**

Even though addiction specialists readily acknowledge that withdrawal from nonprescription drugs like heroin or cocaine causes people to become physically sick, there is no acknowledgement by psychiatrists that withdrawal from psychiatric drugs can be every bit as painful as street drugs. For this reason, many mental health consumers feel hopelessly "stuck" on their "meds" even as their physical health declines and withdrawal may be medically warranted.

Books, Articles, and other Resources

· A guide from Dr. Breggin: mindfreedom.org/breggin-guide-prescribers-patients

· Mad in America's online course on psychiatric drug withdrawal: mindfreedom.org/mad-guide-drug-withdrawal

· A free handbook written by Will Hall, psychiatric survivor, and published by the Icarus Project: mindfreedom.org/will-hall-coming-off-drugs

· A list of relevant books and other resources from MindFreedom International: mindfreedom.org/mindfreedom-quitting-psychiatric-drugs

· mindfreedom.org/quitting-drugs-online-group

· Video: *How to Stop Taking Antidepressants Safely: A Scientific Explanation:* mindfreedom.org/youtube-quitting-drugs-safely

· An inspiring article about achieving psychiatric drug withdrawal and creating noncoercive healing communities, with resources for reframing your "illness": mindfreedom.org/beyond-withdrawal-meds-clarity
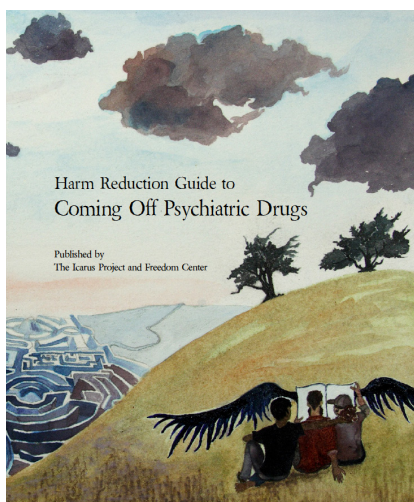
Medication Withdrawal Programs and Professionals

Inner Fire, a newly established year-long program in Vermont: **innerfire.us**

Alternatives to Meds, a clinic in Arizona: **alternativetomeds.com**

Directory of Medical Practitioners who support people withdrawing from psychiatric drugs: **madinamerica.com/provider-directory**

Pajaro Valley Sunrise Center, a developing project: **thesunrisecenter.org**

Inner Compass Initiative: **theinnercompass.org**

Blogs and Forums

Everything Matters: Beyond Meds, a blog by Monica Cassani for people withdrawing from psychiatric drugs: **beyondmeds.com**

A forum for people to post questions and comments about psychiatric drug withdrawal: **mindfreedom.org/mad-forum-drug-withdrawal**

A place for people to connect and share resources founded by Laura Delano, psychiatric survivor: **mindfreedom.org/inner-compass-forum**

Facebook group involving antidepressant withdrawal: **facebook.com/survivingantidepressants**

Facebook group involving antipsychotic withdrawal, especially from a drug called Abilify: **facebook.com/abilify.danger**

Kelly Brogan, MD: **kellybroganmd.com**

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Items for Action

1. Participate in a psychiatric drug withdrawal survey: **mindfreedom.org/maastricht-university-survey**

2. Are you experiencing a drug side effect? Get your free **RxISK** Report to find out! **rxisk.org/experiencing-a-drug-side-effect**

3. Ask the mental health agency in your community if they would sponsor a psychiatric drug withdrawal support group.

Notes:

Shock

> **"If not in our era, in the future, people everywhere will look with as much horror on our lobotomies, our insulin comas and electric shocks, and our other methods of damaging the brain as we now look upon the cruelties—chains, purgatives, spinning chairs, wet packs, and the like—visited upon asylum inmates in an earlier age."**
>
> *–Eileen Walkenstein, US psychiatrist*
> *personal communication, 20 December 2005*

"Shock involves the application of two electrodes to the head to pass electricity through the brain with the goal of causing an intense seizure or convulsion. The process always damages the brain, resulting each time in a temporary coma and often a flatlining of the brain waves, which is a sign of impending brain death. Flatlining is also called the 'postictal suppression' or 'electrical silence' of the brain waves and brain function that routinely follows the ECT seizure. (Suppes et al., 1994). After one, two, or three ECTs, the trauma causes typical symptoms of severe head trauma or injury including headache, nausea, memory loss, disorientation, confusion, impaired judgement, loss of personality, and emotional instability. These harmful effects worsen and some become permanent as routine treatment progresses."*–Dr. Peter Breggin,* breggin.com/ect-resources-center

Litigation for ECT Survivors

Recently, it was announced by Dr. Peter Breggin that a long-awaited major electroconvulsive therapy case that was on the eve of trial just settled to the satisfaction of the injured ECT patients and the DK Law Group, LLP by trial attorney David M. Karen in California. Read full announcement: **mindfreedom.org/mad-ect-trial**

Dr. Breggin, the expert witness in the case, has stated that this is a major development because it means that in the future, a reasonable jury could find that:

· The ECT device manufacturer failed to warn plaintiffs' treating physicians of brain damage resulting from ECT, leading to the oft-reported and acknowledged symptoms of permanent memory loss and cognitive impairment.

· The ECT device manufacturer was in violation of the relevant federal regulations.

· Plaintiffs suffered brain damage as a result of ECT.

· The ECT device manufacturer caused plaintiffs' brain damage through failure to warn their treating physicians of brain injury or to investigate and report allegations of brain damage and permanent memory loss to the FDA, so that information would be available to the public.

1948 advertisement in Time Magazine *by Northwestern National Life Insurance Company.*

Resources for Activists

"Electroshock Quotationary on ECT" by Leonard Roy Frank: **mindfreedom. org/electroshock-quotationary-frank**

"Shock 'Treatment' is Not Safe and Provides Little If Any Benefit" by Philip Hickey: **mindfreedom.org/behavior-shock-article**

"The Need to Ban Electroconvulsive Therapy" by Dr. Peter Breggin **mindfreedom.org/breggin-need-ban-ect**

"Brain Disabling Treatments in Psychiatry" by Dr. Peter Breggin **mindfreedom.org/breggin-brain-disabling-treatment**

ECT Justice! **ectjustice.com**

A website devoted entirely to ECT resources: **ectresources.org**
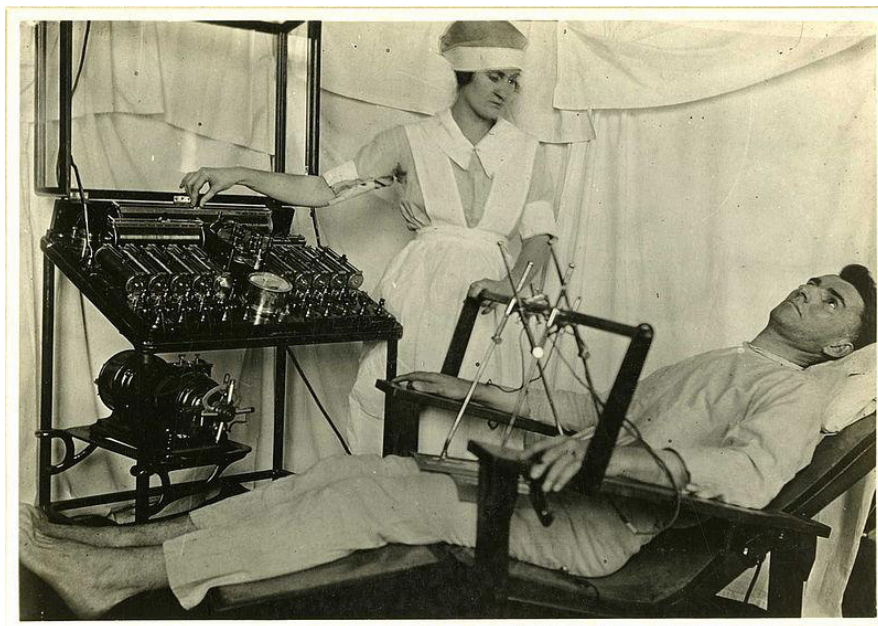
Otis Historical Archives National Museum of Health and Medicine/ Wikimedia Commons (CC by SA 2.0)

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Items for Action

- ECT Survivors: Share your Story: **ectjustice.com/time-voices-heard**

- Participate in a Survey: **ectjustice.com/ect-questionnaire**

- MindFreedom Ireland has been organizing an annual ECT protest for over a decade! View their website and contact MindFreedom Ireland founders Mary and Jim Maddock for more tips on how to organize an ECT protest in your community: **mindfreedomireland.com**

- If you or a loved one are still suffering from lingering side effects of ECT treatment performed within the last few years (or were misled/advised that ECT was not the cause of your lingering issues from earlier ECT treatment), our experts have determined that brain damage is the likely cause. While testing is required, if you were not warned of the risk of brain damage or permanent impairment of cognitive ability as a risk that may occur from ECT and would like more information to determine if remedies are available to you, feel free to send the following information to **ect@dk4law.com**:

    Name:
    Address:
    Cell #:
    Email address:
    # of ECT sessions:
    Date of last ECT:
    State of residence:
    Location of treatment:
    Summary of post-ECT complaints and duration:
    Description of any Post-ECT treatment or testing:

TREE

An oak tree mitigates the effects of excess carbon in the atmosphere, providing oxygen, shade, wind protection, wildlife habitat, nutrients, beauty, and inspiration. In this section, readers learn ways of flourishing by building community, pursuing service, giving/receiving peer support, and engaging in activism.

Other Ways of Supporting Individuals in Distress

Peers Supporting Others In Crisis Without The Use of Force or Drugs: A Revolutionary Concept

Lack of alternatives for people in crisis is in itself a crisis. Nonforce, nondrug alternatives are not widely available. People call the police or go to the emergency room of their local hospital due to lack of options.

Calling the police to deal with a mental health crisis is risky. According to the *Washington Post*, 998 people in the US have been killed by the police in 2018: **mindfreedom.org/wp-killed-by-police**. 25 percent of the victims were considered to be experiencing a mental health crisis. This doesn't include deaths in prisons and jails. These tragedies are preventable.

Individuals are routinely traumatized in psychiatric settings. The use of restraints, handcuffs, shackles, and injectable drugs often exacerbate PTSD symptoms and trigger powerlessness, especially among people with abuse histories. Read more: **mindfreedom.org/patients-report-psychiatric-trauma**

Survivors of harmful treatment by force may have lingering fear and cease to seek help. The breakdown of trust between psychiatric survivors, first responders, and treatment providers is a preventable tragedy.

Activists and leaders within the psychiatric survivor community have successfully created alternative models for supporting people in distress. They point out that crisis hotlines and programs should not veer people by default to punitive systems or services steeped in the biomedical model that routinely use force and coercion.

Psychiatric survivors and leaders in the psychiatric survivors movement have called for a complete overhaul of how communities support people in distress.

Open Dialogue, and the Peer Respite model are very promising approaches for supporting people in crisis. Both are respectful of a person's agency and right to reject unwanted treatment. They are covered in detail later in this section.

One training called Emotional CPR has been adopted specifically for first responders. View and download at:

mindfreedom.org/first-responders-emotional-cpr. Other trainings developed by people with lived experience are mentioned below, as well as in the chapter "*Peer Support.*"

Individuals often experience a crisis due to adverse situations or a history of trauma. They may be feeling isolated, marginalized, and exhibit strong emotions. They may be cognitively impaired due to a preexisting disability, or intoxicated due to recreational drug use, alcohol consumption, or legal drugs taken as prescribed (see adverse drug reactions in chapter entitled Psychiatric Drugs and Iatrogenic Harm). They may also be experiencing withdrawal effects from any of the above. To network with people who have experienced adverse psychiatric drug reactions resulting in involvement with police, connect with these facebook groups: **Prescripticide:** facebook.com/prescripticide and **Legal Death–In Drugs We Trust:** facebook.com/legaldeath

TREE

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First responders are often under equipped to deal with people in crisis who have special needs or communication issues. They are trained to assume that a person is armed and dangerous.

Readers who want to prevent or plan for a potential crisis should review the resources listed under "Psychiatric Advance Directive" and "Protection and Advocacy."

If You or Someone You Love is Experiencing a Crisis

Hotlines are generally staffed twenty-four hours per day to help people in crisis. Warm lines have limited hours. Every hotline is different, but most are staffed by mental health professionals who are steeped in the biomedical model.

Under the biomedical model, there is a rush to medicalize distress and extreme states by framing them as "mental illnesses" or "chemical imbalances" requiring immediate psychiatric intervention, usually in restrictive settings resulting in forced injections and shock. If you contact a suicide hotline, it is your right to ask if everything you say is private in order to avoid activating overly restrictive measures that are potentially disruptive and harmful.

Find a Peer Warm Line Near You

Peer warm lines employ people who are "experts by experience" and have a different perspective as it concerns privacy and the use of psychiatric interventions that may harm you. To find a peer-run warm line near you, visit the National Empowerment Center website: mindfreedom.org/national-empowerment-center-website

HELP IS AVAILABLE

TREE

Start a Peer Warm Line In Your Communit y

If you don't have a peer-run warm line in your community, speak up for change! For resources to help you create a peer-run warm line in your community, visit: mindfreedom.org/peer-run-warm-line-video

Warm Line for People on West Coast, USA Dave Romprey Warm Line

800-698-2392

Hours of Operation: 9am-11pm (Pacific) Monday through Sunday

The David Romprey Peer Warmline is a model for other communities that need an alternative to traditional crisis call-in services. Initially, it operated five hours a week and received two to three calls per week. Today it operates more than 100 hours per week and logs close to 15,000 calls per year. They offer a tool kit for sale on their website: communitycounselingsolutions.org/warmline

Warm Line for People on East Coast, USA Western Mass Peer Support Line

888-407-4515

Mondays through Thursdays, 7-9pm (Eastern)
Fridays through Sundays, 7-10pm

Peer Respites

Peer respites are voluntary, nonlocked residences where individuals experiencing a crisis can stay for up to two weeks and receive round the clock support from peer staff. A full description

Afiya house in Massachusetts

of a peer respite can be found in this section, as well as a video tutorial on how to create a peer respite in your community.

The *Afiya* house (**westernmassrlc.org/afiya**) run by the Western Massachusetts Recovery Learning Community, and *Second Story* run by Encompass Community Services in Santa Cruz (**mindfreedom.org/second-story-encompass**) are two examples of peer-run respites in the US.

For resources to help you advocate for a peer respite in your community see: **mindfreedom.org/ncmhr-peer-respite**

Families Healing Together

Families Healing Together is an eight-week online class written and facilitated by Krista MacKinnon, a Canadian-based educator and organizer whose work is informed by her lived experience of recovery from a bipolar diagnosis. It offers a critical perspective of the "biomedical model of mental illness" and "moves families past fear and confusion into new states of wholeness, well-being and connectedness."

One of the benefits of this training is the ability to network with other people from the privacy of your home. Another is to give and receive mutual support from people experiencing similar situations. For more information, or to register for the next class, visit: familieshealingtogether.com

Unlike the Family to Family training by National Alliance for the Mentally Ill (NAMI), which is funded by a drug company, Families Healing Together is independently funded and was developed primarily by people with lived experience.

Icarus Project Crisis Toolkit

The Icarus Project is a breath of fresh air if you are searching for alternative ways of making it through a crisis without going to the hospital. They offer a crisis tool kit on their website which states:

> "We're so glad you found us. When you or someone close to you goes into crisis, it can be the scariest thing to ever happen. You don't know what to do, but it seems like someone's life might be at stake or they might get locked up, and everyone around is getting stressed and panicked. Most people have either been there themselves or know a friend who has been there. Someone's personality starts to make strange changes, they're

TREE

not sleeping or sleeping all day, they lose touch with the people around them, they disappear into their room for days, they have wild energy and outlandish plans, they start to dwell on suicide and hopelessness, they stop eating or taking care of themselves, or they start taking risks and being reckless. They become a different person. They're in crisis." mindfreedom.org/icarus-toolkit

Emotional CPR

Emotional CPR was developed by people who have learned from their own experience how to get through an emotional crisis and integrate the experience into a broader understanding of themselves and others. Their website states:

> "Emotional crisis is a universal experience. It can happen to anyone, at any time. When we are exposed to this extraordinary situation, we develop amazing and creative ways to protect ourselves. To onlookers, these protective mechanisms may look very odd, even 'crazy.' To us, they have meaning. Through using eCPR we can better understand and overcome our fear of seemingly unusual behavior brought on by an emotional crisis. Through eCPR we learn how to form supportive connections that empower the person in emotional crisis so they are able to feel revitalized and quickly resume meaningful roles in the community." emotional-cpr.org

Spiritual Crisis Network

facebook.com/SpiritualCrisisNetworkUK
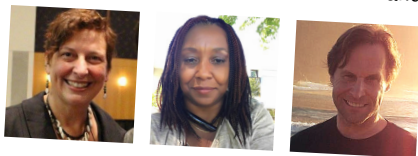
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An example of a flyer
created by a grassroots organization
called Rethinking Psychiatry in Portland, Oregon

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Items for Action

Create opportunities to educate others in your community about alternative ways of supporting people in crisis. Procure a location, invite speakers, and publicize, events on community calendars, radio stations, flyers, and bulletin boards. Here is an example of a flyer created by a grassroots organization called Rethinking Psychiatry in Portland, Oregon: **mindfreedom.org/ sample-flyer**

Creating a peer-run respite in your community requires lots of planning and support. Start by educating lawmakers and policy makers about peer-run respites. Arrange private meetings with lawmakers in your community or testify in town hall meetings. Go prepared by putting together brief talking points. Practice with a friend in advance. To put together bullet points, share your personal story or collect stories from psychiatric survivors. Augment stories with facts. Evidence for the effectiveness of peer-run respites can be found: **mindfreedom.org/evidence- peer-run-respites**

Notes:

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The Growth and Expansion of Peer Support

"We call upon all people committed to human rights to work together to build a mental health system that is based upon the principle of self-determination, on a belief in our ability to recover, and on our right to define what recovery is and how best to achieve it."

–Statement of Concern and Call to Action by "Highland 30"

mindfreedom.org/kb/highlander-2000

One of the most stunning deficits of the mental health system is the silencing of psychiatric survivors. The mental health system pours hundreds of millions of dollars annually into research conducted by "experts" to develop programs and services that are then delivered by clinical "experts." But notably missing from within this multibillion-dollar industry is the collective wisdom of the hundreds of thousands of experts by experience.

Where are the voices of psychiatric survivors—those who identify with having been harmed by psychiatric "treatment"? What can experts learn from those who achieve mental and emotional wellness by rejecting standard psychiatric treatment in favor of less harmful, alternative approaches? Why aren't researchers and clinicians falling over themselves to tap into this knowledge base?

TREE

Psychiatric Survivors Movement

The evolution of peer support can be traced to psychiatric survivors who started their own self-help groups. Advocacy for a recovery model emphasizing human rights organically sprang from the Psychiatric Survivor Movement in the process of activists giving and receiving mutual support while exploring alternative approaches to standard psychiatric interventionss.

Some groups like MindFreedom International and the Freedom Center focused on activism and human rights. Other peer groups such as the National Empowerment Center (NEC), founded by Dan Fisher, MD, engaged with researchers and government-funded programs such as Substance Abuse and Mental Health Services Administration SAMHSA, **samhsa.gov**, laying the groundwork for innovations in mental health care, such as the practice of hiring peers.

By creating partnerships with government programs, NEC hoped to create an evidence base that could be tapped to veer resources away from harmful treatments into more humane and effective ones. In addition, they worked on creating best practices and training for other peer providers and organizations.

Leaders within the Psychiatric Survivors Movement provided a much-needed counter narrative to the messages of hopelessness that practitioners of the medical model frequently conveyed to their patients. Judi Chamberlin, a pioneer of the Psychiatric Survivors Movement, famously declared, "We are the evidence!"

Dan Fisher describes the importance of hope in recovery in his article *"We Are Whole People, Not Broken Brains."* View article at: **mindfreedom. org/whole-people-dan-fisher**

Formalizing Peer Support

Some leaders in the Psychiatric Survivor Movement believed that the best way to improve the mental health system was to formalize peer support and make it more available. For decades, activists pressured mental health agencies and hospitals to hire people with lived experience to deliver services in clinical settings. See timeline below.

This goal has been partially realized. Today, it is estimated that 25,000 peer specialists work in the mental health system. Some peer activists believe that this number is too low and prioritize the hiring of many more peers.

Psychiatric Rehabilitation: Natural Allies

Human rights activists found natural scientific allies in the field of "psychiatric rehabilitation" and the disabilities rights movement.

For example, William Anthony of the Center for Psychiatric Rehabilitation conducted research confirming the value of supportive services that enabled people being discharged from mental institutions to live independently in their communities.

Scientific allies like William Anthony joined psychiatric survivors in calling for more humane and effective options than simply releasing people from institutions with a handful of pills. For scientific validation of what peer advocates had been saying for years—that social integration matters more than pills—read this article by William Anthony and

TREE

three of his colleagues defining psychiatric rehabilitation and why it is important: **mindfreedom.org/psych-rehab-anthony**

In his article, Dr. Anthony cites an important longitudinal, controlled study by Dr. Courtenay Harding revealing an astonishing rate of recovery involving a group of ex patients who were followed for thirty years after they were discharged. This controlled study revealed that the recovery rates were the highest for those who discontinued medication but received high levels of social support/reintegration services.

History of Peer Support

One of the first challenges encountered by activists was compelling lawmakers and policy makers to create formal roles for peers in the mental health system. To do this, early supporters started to adopt standards and training and created an evidence base. These pieces took decades to fall into place.

Expanding Peer Support in the United States: Some Milestones

1985   The National Institute of Mental Health issues a request for proposals for consumer-run national technical assistance centers.

1986   The first group of psychiatric survivors/consumers trained to work for the mental health system as professionals were trained in Denver, Colorado, as Consumer Case Manager Aides (CCMAs) by Pat Risser. These "peer providers" were the first to provide services that were billable to Medicaid under the Medicaid Rehabilitation Option Waiver in effect for Colorado.

1989   "Mental health consumer participation on boards and committees: Barriers and strategies." *Canada's Mental Health,* June, 8-11. by M. B. Valentine and P. Capponi.

1989   The Well Being Project (Campbell & Schraiber, 1989, Campbell, 1992) added to understanding the concept of quality of life from the perspectives of consumers.

1993   Work on creating Nation's first civil service Peer Specialist position begins in New York State. Celia Brown is named director of Peer Specialist Services.

1991   "Alternatives '91" conference in Berkeley draws over 2,000 participants for the largest consumer/survivor conference ever. Howie The Harp calls this the largest voluntary gathering of mental patients in the known galaxy. It was also the last time the Alternatives conference was held on a college campus.

1991   Survivors Poetry set up in London to run workshops and performances, which spread to many other cities.

1992   New York State OMH appoints first Office of Consumer Affairs (Darby Penney).

1992   National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) is founded.

1993   "From lab rat to researcher: The history, models, and policy implications of consumer/survivor involvement in research." Paper presented at the fourth annual national conference of state mental health agency service, research, and program evaluation, Annapolis, MD. by Jean Campbell, Ruth Ralph, and Robert Glover.

1993   Consumers/survivors reform the system, bringing a "human face" to research. Resources, 5, 3-6. by A. Scott.

1993   Movement leaders met with President Bill Clinton as part of a historic White House dialogue with twenty-eight leaders of major disability constituencies. Participants included Judi Chamberlin.

1994   The first class of the Consumer Service Training graduates in Contra Costa County, California. This is the first training for Community Support Workers where the curriculum, class design, and training were all implemented and taught by other consumers/survivors (Pat Risser, Jay Mahler, Mary Carley, etc.) with a recovery orientation.

1994   Darby Penney, Celia Brown, Peter Stastny, and Neil Covatta were successful in creating the first civil service Peer Specialist Title in the United States.

The milestones above are extracted with permission from Lauren Tenney from **Our Story of Commitment: A Living Document**, which can be viewed at: **laurentenney.us/ourstory-of-commitment.html**

Recovery Model

Recovery means different things to different people. There is no consensus even among psychiatric survivors and mental health consumers on a one-size-fits-all definition.

MindFreedom endorsed this conception of recovery in the form of a downloadable brochure written by Steve Morgan, a psychiatric survivor, at **mindfreedom. org/brochure-recovery-morgan**

Celia Brown, long time psychiatric survivor activist

Challenges Encountered by Peer Support Advocates

Darby Penney, a leader in the psychiatric survivor movement, defines two types of peer support: *peer-delivered peer support* and the *peer staff model.*

She explains why this distinction is important in an article entitled: *"Who Gets to Define Peer Support?"* in a blog posted on *Mad in America.* Read entire post here: **mindfreedom.org/define-peer-support-article** *An excerpt from this article:*

> "New York became the first state to establish a Peer Specialist civil service title. The position was developed primarily by policy-making staff with psychiatric histories, motivated by the desire to bring the values and principles of grassroots peer support into paid peer staff roles. However, this is not

TREE

what happened in practice. The peer specialists' ability to adhere to peer support values was compromised by clinicians and administrators who did not understand or support the principles, including many who actively worked to undermine them."[1]

As more and more mental health agencies began to hire peer "specialists," the role of peer support evolved to something much different from what it originally represented. Ms. Penney writes:

"While there is no standard definition, many states, provider organizations, and government agencies have developed peer specialist or similar job titles, such as peer mentors, peer support specialists, recovery support specialists, recovery coaches. These job titles apply to employees with psychiatric histories who work in paraprofessional roles in traditional mental health programs.[2] Peer workers in traditional programs generally do not offer 'peer support,'

Darby Penney

but provide clinical, ancillary, and/or paraprofessional services that are indistinguishable from those provided by non-peer staff. While peer staff may be providing 'clinical' services, they do not have pay equity with actual clinical staff. Relationships between peer staff and service users are usually hierarchical, as opposed to the horizontal relationships of peer-developed peer support, and these workers are seldom exposed to the principles and practices of peer-developed peer support."

1 Stastny, P., & Brown, C. (2013). *Peer specialist: Origins, pitfalls and worldwide dissemination Vertex*, 24(112), 455.
2 Davidson, L., Bellamy, C., Guy, K., & Miller, R. (2012). Peer support among persons with severe mental illnesses: a review of evidence and experience. *World Psychiatry*, 11(2), 123-128.

Ownership of Recovery Principles

In **Behind the Rhetoric: Mental Health Recovery in Ontario,** author Jennifer Poole critiques the rhetoric used by proponents of the recovery model. She argues that the recovery model borrows concepts from biomedical discourse and therefore is not as new and empowering as proponents of the recovery model want us to believe. See review by Stephanie Power: mindfreedom.org/power-review

In the article *"LIVING WELL,"* service user Mary O'Hagan describes how recovery has been redefined in New Zealand:

> "People in New Zealand had been talking about recovery for some years and there was a lot of support for the concept. But we knew some service users didn't like the word. 'Recovery takes you back to where you were, but my experience transformed me.' 'I'll always have mental health problems so I'll never recover.' 'I don't believe I had an illness but recovery implies I did have one.' 'I don't see my madness as undesirable, so what is it I need to recover from?' 'To recover means to cover up again, but I don't want to cover up my distress.'"

She also cites problems of importing recovery principles from other cultures.

> "Recovery is an import from America; second, the Americans, in emphasising recovery as an individual process, have seemed to overlook that it is a social process as well; and third, that recovery in America evolved out of psychiatric rehabilitation and was perhaps driven more by professionals than by service users." mindfreedom.org/living-well-mary-ohagan

Some argue that the formalization of peer support presents new challenges. Brooke Feldman, social worker/activist, writes about what she calls the "co-optation" of "peer activism" in the article: *The Co-option and Oppression of a Social Justice Movement: Professionalized Peer Support Services."* Read here: mindfreedom.org/cooption-peer-support-article

She states: "Institutionalized peer support has had a positive impact in many people's lives for sure, but from a larger standpoint, the institutionalization of peer support has ultimately demobilized the very social justice movement from which it was birthed."

Other peer leaders including Sascha Altman DuBrul, cofounder of The Icarus Project, are more optimistic about the role of peer support in the mental health system. He argues that the high number of peers now employed by the mental health system, about 25,000 by his estimate, forms a critical mass needed for organizing and reshaping the mental health system, completing and refining the work started by peer recovery advocates thirty years ago. mindfreedom.org/building-network-peer-support

There is no consensus among activists on whether or not to standardize, certify, and train peers to deliver services in clinical settings, and if so, how this would happen.

Some advocates claim that standardizing and certifying peer specialists defeats the underlying value of peer support. Other peer advocates argue that peer training helps individuals to explore baggage from media exposure as well as our own experiences receiving services in the mental health system.

Here's what Sera Davidow has to say in her book, ***Peer Respite Handbook: A Guide to Understanding, Developing and Supporting Peer Respites:***

> "It's also worth noting that there are many people who find the idea of training people in peer support objectionable. This is based on the belief that peer-to-peer support is about being human with one another, and that training does little but get in the way of that. However, it's worth remembering that even people who've never been through clinical training have been exposed to clinical ideas through media and a variety of other sources (including their own experiences receiving services). Good training for peer support will help people examine their worldview, and understand what assumptions and beliefs they might be bringing to the respite, regardless of where they come

TREE

from. It will also give people a chance to talk through any fears they might have, practice ways to connect or address conflict, and so on. Ultimately, training is about giving space for people to learn together and build confidence, and should not be discounted."—Davidow, Sera. ***Peer Respite Handbook: A Guide to Understanding, Developing and Supporting Peer Respites.*** *Western Mass Recovery Learning community. Denver: Outskirts Press, 2017.* mindfreedom.org/peer-respite-handbook
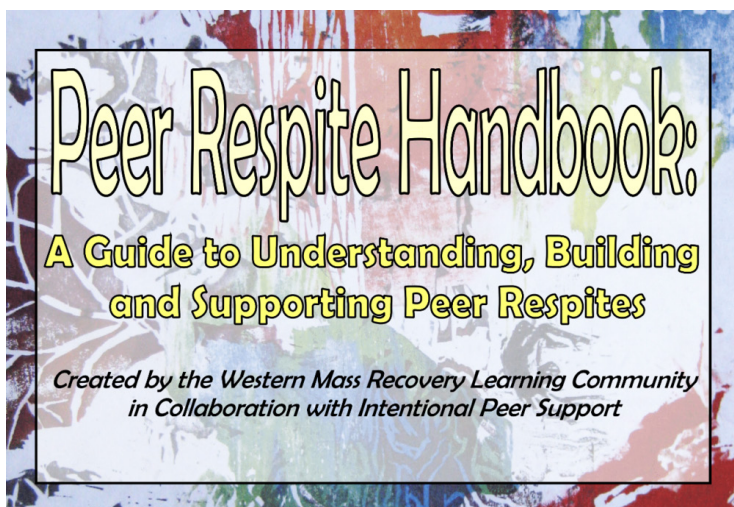
Items for Action

If you have difficulty finding peer support in your community, chances are your state does not enjoy a strong consumer voice in the development of mental health services. To correct this, read the following primer by the **National Empowerment Center** on how to create statewide consumer/survivor organizations in your state: mindfreedom.org/national-empowerment-center-primer

Consider asking the mental health agency in your community to host an "Intentional Peer Support" training! Or ask your church, employer, or support group to host one: intentionalpeersupport.org

Challenge all mental health care workers and administrators to come out of the closet about *their* history of distress, anxiety, depression, etc. Everyone has mental or emotional challenges.

Using tactics described in the Grove section of this handbook, ask the lawmakers and policy makers in your community to hire more peers in your community. Where could peer specialists do the most good in your community? First responders? Shelters or food banks? Hospitals? Mental Health Care agencies? Hold a town hall meeting, distribute a survey, or conduct a focus group.

If there is no peer-organized support group in your community, consider starting one. Here's a summary of studies, articles, and resources which can potentially help: mindfreedom.org/peer-organized-support-group

Consider starting a **MindFreedom** affiliate in your community! More information on starting one: mindfreedom.org/member-folder/as/affiliates-sponsors

TREE

Peer Support

> **"Peer-developed peer support is a non-hierarchical approach with origins in informal self-help and consciousness-raising groups organized in the 1970s by people in the ex-patients' movement. It arose as a reaction to negative experiences with mental health treatment and dissatisfaction with the limits of the mental patient role."**
>
> *–Darby Penney, Mad in America*
>
> mindfreedom.org/define-peer-support-article

Psychiatric survivors who worked tirelessly for decades to promote, formalize, and expand access to peer support encountered many problems that are discussed in the chapter "The Growth and Expansion of Peer Support." These problems are ongoing, and the fidelity and future of formalized peer support rests on activists and leaders resolving these problems.

This chapter explores peer support not from an activist's perspective but from the human perspective. All of us need periodic validation and reminders that we are important. All of us need a social community which we can tap into to give and receive mental and emotional support, especially during difficult times.

Sometimes our social network—family, friends, neighbors, etc.—is adequate help through difficult times. Sometimes our social network is not enough. At those times, we may seek professional help. Sometimes we may be subjected to psychiatric intervention by force or coercion due to lack of alternatives.

If you or someone you love has been forced or coerced into receiving psychiatric "treatment" due to a lack of alternatives in your community, any problems and unfortunate circumstances you or your loved one faced may have been greatly compounded.

As we have seen in the chapter "Treatment by Force," involuntary treatment in a restricted environment can greatly disrupt someone's life and cut them off from their social networks. It subjects people to stigmatizing labels and harmful treatments such as powerful neuroleptics and shock.

If you need support to help you recover from psychiatric harm and abuse, this chapter is dedicated to helping you or your loved one find peer support. It also offers tips on embodying the changes you wish to see in the mental health system by learning from the collective wisdom of psychiatric survivors who work outside the mental health system.

Defining Peer Support

"Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain. When people find affiliation with others they feel are 'like' them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships." (*Mead, 2001*)

Peer support is not the same as support from a psychiatrist, social worker, counselor, psychologist, or other paid therapist.

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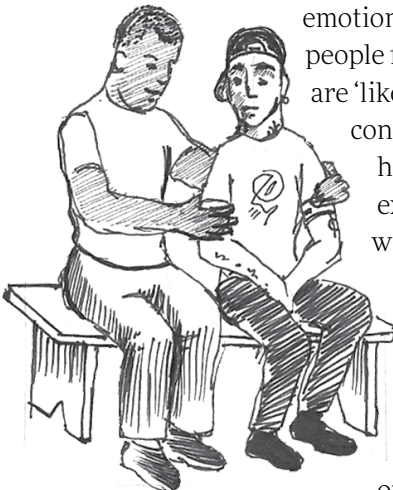
"A major qualification of working in a peer role is having been through significant life struggles (trauma, psychiatric diagnosis, addiction, homelessness, hospitalization, losing custody of one's children, etc.), and having an understanding of the marginalization and losses that can result. There is something extremely powerful about sharing one's story with someone else who has walked in their shoes (or, at least, been in the same shoe store) and has felt similar pain from the inside out. It's all the more powerful to then have that person be willing to talk about their story. In many traditional spaces, it is frowned upon to share too much of one's own history or life beyond the most superficial facts. There is a fear that it may burden the other person, making them feel worse. There also sometimes seems to be a fear that respect for the person in the supporter role may be lost if they reveal their vulnerabilities. Whatever the reason may be for this closed-offedness, the fact is that, time and again, it has been shown that offering up relevant bits of who one is in a genuine way creates a connection which helps others to feel heard and seen in deep ways, possibly in even deeper ways than if they were paying for a therapist to see them in a clinical light.

However, peer-to-peer support is about so much more than that. It's really a way of being with someone. Rather than assessing someone or their 'level of safety,' it's about hearing them out and keeping an open mind and heart so that judgement and fear don't get in the way of seeing that person for who they are and how they are struggling. It's about two people sitting side by side without a clinical veneer or power dynamics at play. There is no expert, and knowledge is a shared entity. It is about two people who have seen the depths of hell looking at each other honestly and building a connection from which both people can learn and grow."–Davidow, Sera. ***Peer Respite Handbook: A Guide to Understanding, Developing and Supporting Peer Respites.*** Western Mass Recovery Learning Community. Denver: Outskirts Press, 2017.

Studies Confirming the Effectiveness of Peer Support

mindfreedom.org/peer-supported-studies

A randomized controlled trial finds that receiving peer support from individuals with similar lived experiences reduces one's risk of readmission to an acute crisis center: **mindfreedom.org/peer-support-reduces-readmission**

This article presents findings from a randomized controlled trial of a peer-support mentorship intervention designed for individuals with serious mental illness and frequent, recurrent psychiatric hospitalizations.

Status Quo Self-help Groups

Mental Health America (MHA) lists organizations that can help people find peer support in their communities depending on their diagnosis or orientation: **mentalhealthamerica.net/find-support-groups**

Many of the self-help groups listed on this website are appropriate for individuals who identify with their diagnostic labels and consider the mental health system services they receive to be helpful.

It is notable, though, that some of the mental health support groups listed on MHA's website accept large sums of money from drug companies. For instance, the Depression and Bipolar Support Alliance (DBSA) lists among its sponsors the following drug companies:

· Alkermes, Inc.

· Allergan, Inc.

· AstraZeneca

· Humana Foundation, Inc.

· Janssen Pharmaceutical

· Lundbeck LLC

· Neurocrine Biosciences, Inc.

TREE

- Otsuka America Pharmaceutical, Inc.
- Sunovion Pharmaceuticals, Inc. and Takeda Pharmaceuticals North America, Inc.

MindFreedom International (MFI) receives calls from individuals in distress who are seeking support but do not trust the mental health system based on negative past experiences.

For this reason, MFI frequently encourages people to find peer support groups and peer organizations in their community that operate independently, *i.e. do not rely on government funds or money from drug companies.* If one is not available, as is often the case, MFI encourages people to create their own. This is not easy but most of the organizations listed below started from very humble beginnings!

To Find Peer Support in Your Community

Hearing Voices Network

The Hearing Voices Support Group Network is a growing, international network of self-help groups. Groups are facilitated by a trained individual, usually someone with lived experience, and they welcome all individuals who identify with hearing voices. Individuals who have unusual beliefs or experience extreme states are also welcome. More detailed information, as well as information to help you or a loved one locate a chapter in your community, can be found in the chapter "Hearing Voices."

Centers for Independent Living

Centers for Independent Living (CILs), **lilaoregon.org/centers-for-independent-living.html**, are private nonprofit organizations that assist people with disabilities to gain independence, access, and inclusion in society. This includes people who identify with psychiatric disabilities. Services are usually free of charge.

To be a certified CIL, the organization must offer these core services:

1. Information and referral
2. Independent living skills training
3. Individual and systems advocacy
4. Peer counseling
5. Transition: services that facilitate transition from nursing homes and other institutions to home and community-based residences with the necessary supports and services, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life

An example of a local ILA in Eugene, Oregon

To see if there is a CIL in your community, view a directory: **mindfreedom.org/centers-independent-living-directory**

TREE

Peer Activist Organizations

MindFreedom International (MFI) has many affiliates. Affiliates are aligned with MFI's mission to promote human rights, and they can provide psychiatric survivors opportunities to network with peers and give/receive mutual support. To see if one exists in your community, go to: **mindfreedom.org/mfi-affiliates-sponsors**

If MFI does not have an affiliate in your community, consider starting one! For information on how to start one, read: **mindfreedom.org/mfi-affiliates-sponsors-faq**

Peer Training

Intentional Peer Support

Intentional Peer Support (IPS) is a nonprofit organization dedicated to training individuals (including mental health professionals) on supporting people in nonclinical ways. It is a way of thinking about purposeful relationships. It is a process where both people (or a group of people) use the relationship to look at things from new angles, develop greater awareness of personal and relational patterns, and support and challenge each other. IPS has been used in crisis respite (an alternative to psychiatric hospitalization), by peers, mental health professionals, families, friends, and community-based organizations.

IPS is different from traditional service relationships because:

- It doesn't start with the assumption of a "problem." Instead, people are taught to listen for how and why each of us has learned to make sense of our experiences, and then to use the relationship to create new ways of seeing, thinking, and doing.

- IPS promotes a "trauma-informed" way of relating. Instead of asking "what's wrong?" we think about "what happened?"

- IPS looks beyond the notion of individuals needing to change and examines our lives in the context of our relationships and communities.

- Peer Support relationships are viewed as partnerships that enable both parties to learn and grow, rather than as one person needing to "help" another.

- Instead of a focus on what we need to stop or avoid doing, we are encouraged to move toward what and where we want to be.

intentionalpeersupport.org

> Screen a public showing of this keynote speech by Shery Mead, the founder of Intentional Peer Support: **mindfreedom.org/ shery-mead-speech**

Icarus Project

According to the website of The Icarus Project, "The Icarus Project is a support network and education project by and for people who experience the world in ways that are often diagnosed as mental illness. We advance social justice by fostering mutual aid practices that reconnect healing and collective liberation. We transform ourselves through transforming the world around us."

The Icarus Projects sends trainers—people with lived experience—to college campuses, organizations, and communities to talk about mental health and collective well-being.

"The duration and specific content of talks, workshops, and trainings are very flexible–TIP-led events have ranged from one hour to one week in length, and can be tailored to audience needs! All workshops are available in English and Spanish and some may be delivered online if bringing facilitators to you is cost prohibitive."

theicarusproject.net

Re-evaluation Counseling

According to its website, Re-evaluation Counseling is "A process whereby people of all ages and all backgrounds can learn how to exchange effective help with each other in order to free themselves from the effects of past distress experiences.

In its basic form, the practice of Co-Counseling simply consists of two people taking turns listening to each other.

Co-Counseling 'turns' or 'sessions' can be as long or as short as you have time for. Even a few minutes shared with your Co-Counselor can make a big difference in how you are able to think and function, and two hours shared is that much better.

It also works well to get a small group of people together to take turns listening to each other. (RC calls this a 'support group.') Each person gets a roughly equal amount of time to talk while the rest of the group listens.

If you try Co-Counseling and you decide that you'd like to learn more, you may get in touch with the main Re-evaluation Counseling office by emailing **ircc@rc.org** and asking if there are any Co-Counselors who live near you: **rc.org**."

Peer Respite Model

> ## "People saw the value in me when I hadn't seen any value in myself for years. Today, I'm at the healthiest place I've ever been. People come and find relationships that are lasting and build a community of support."
>
> *–Jessica Brown,*
> *a former Second Story Peer Respite guest*

A peer respite is a voluntary, short-term overnight program that provides community-based, nonclinical crisis support to help people find new understanding and ways to move forward. It operates twenty-four hours per day in a homelike environment.

To find a peer respite in your community, visit: **peerrespite.net/directory**

Lois McLaughlin, mother of a 2nd Story guest, said the program has helped her daughter avoid "probable hospitalization, which is far more costly for the county."

"Other clients, in addition to my daughter, are consistently kept from psychiatric hospitalization by spending a week or two at 2nd Story."

Purpose of a Peer Respite House

Here's how Sera Davidow describes the purpose of a peer respite house in her book, ***Peer Respite Handbook***: "There are several different ways that people have come to commonly describe the mission of peer respite. These include:

· As hospital diversion

· As an opportunity to turn crisis into learning

· As a non-clinical alternative focused on peer-to-peer supports

· As an opportunity to address issues related to social justice and marginalization

As hospital diversion: A primary aim of peer respite is to support people through difficult times while avoiding hospitalization and other invasive and life-disrupting interventions. This may include supporting someone who has frequently been in and out of the hospital to break that cycle. For some peer respites, it includes supporting someone through a first experience and helping them avoid ever getting into a cycle of hospitalization in the first place. While part of the motivation of hospital diversion is saving the community money, another reason is that hospitalization, especially when involuntary, can be experienced as traumatizing. Even when voluntarily chosen, hospitals can be unnecessarily restrictive or disruptive to someone's life in ways that are not helpful. For example, even a relatively brief hospitalization can impact someone's work or school, leave pets unfed, and bills arriving in the mail unable to be accessed. The option of peer respite, on the other hand, brings to life the promise of 'least restrictive' environments, and allows for people to determine for themselves where they stay.

As an opportunity to turn crisis into learning: In general, people are taught that 'crisis' is bad, and that the focus should be to get out of 'crisis' and then avoid it in the future. Peer respites typically accept that humans can learn as much (if not more) when life is difficult than they

can when everything's great. Therefore, a primary goal when someone stays at a peer respite is to support them in exploring how they've come to walk through the world in the way that they do, and how that is or is not working for them. That may include examining how they make meaning of their life experiences, how they define healing or 'recovery,' and what they do or do not want to change moving forward. It also means not assuming that experiences like hearing voices and self-injury are 'symptoms' to be gotten rid of, but that they may be potentially meaningful ways of coping that could teach us a lot about what is going on for the person in that moment.

As a non-clinical alternative focused on peer-to-peer supports: Some people who stay at a peer respite also regularly use clinical services. Others feel alienated from those services or have never used them and are trying to avoid doing so. Either way, the focus at a peer respite is on non-clinical peer-to-peer support, and the mission is based on the idea that there is great power and wisdom to be found in shared experiences between people who have all 'been there.' Peer respites try to come from a place of mutuality, meaning that it's assumed that everyone—regardless of their specific role—has the potential to learn and grow and contribute based on their connection with others, and that no one person is the 'fixer' or 'holder' of all knowledge.

As an opportunity to address issues related to social justice and marginalization: Although this is not often where the conversation of peer respite begins, it's important to mention right from the start. People with psychiatric diagnoses, people who are poor and limited to using public sector services, non-white folks and so many others who have experienced routine marginalization often lack any kind of choice at all regarding when, how, or where they seek support. Often, these consequences of racism, poverty, and ableism (etc.) have been traumatic themselves, and played a fundamental role in creating or adding to a person's initial distress. As peer respites are rooted in choice and self-determination, they have the potential to become a part of a much broader network of change, but that requires awareness, intention and openness to ongoing learning from day one. Peer support has been shown to prevent readmission to hospitals."

"They provided me community and I no longer felt lost."

–Jessica Brown,

a former Second Story Peer Respite guest

History of Peer Respites

Davidow goes on to say: "The history of peer respite is not clearly documented in any one place, but one thing is clear: Advocacy for peer respites has come from human rights and self-help movements, and has largely been driven by people who have been harmed by, or had their rights violated by, existing systems. Although successful efforts to get new respites up and running often involve partnership with a variety of people and funders, it's important to remember those roots to help remind us why the design and values are so important.

In 1997, the first official peer respite, Stepping Stone, was developed by Shery Mead and friends in Claremont, New Hampshire. Stepping Stone was considered a fully peer-run respite (meaning everyone working there identified as having personal experience with psychiatric diagnosis, trauma or other significant life challenges and it was not under the umbrella of a clinical organization). Rose House was the next fully peer-run respite, opening in 2001 in Poughkeepsie, New York. Additional peer respites opened after that, including the Georgia Peer Respites in 2008. Meanwhile, the creation of 'hybrid' peer respites (respites where everyone employed identified as having personal experience, but existed within the context of a clinical organization) were also underway. Sweetser in Maine was one of the first in 2002. Second Story was another hybrid peer respite that followed several years later in Santa Cruz, California. Some of these respites still exist, some have changed or evolved into other organizations, and some have closed."—Davidow, Sera. ***Peer Respite Handbook: A Guide to Understanding, Developing and Supporting Peer Respites*** Western Mass Recovery Learning community. Denver: Outskirts Press, 2017

Peer Respite Staff

· Peer respites are staffed and operated by people with psychiatric histories or who have experienced trauma and/or extreme states. This means that . . .

· 100 percent of staff have lived experience of extreme states and/or the behavioral health system.

Governance of a Peer Respite

· The peer respite is either operated by a peer-run organization OR has an advisory group with 51 percent or more members having lived experience of extreme states and/or the behavioral health system.

Afiya House

Afiya House is an example of a peer respite. It is a part of the Western Mass Recovery Learning Community (RLC). The RLC strives to create healing and learning opportunities for individuals and the community as a whole. **westernmassrlc.org/afiya**

The Afiya House's website reads:
"Afiya strives to provide a safe space in which each person can find the balance and support needed to turn what is so often referred to as a 'crisis' into a learning and growth opportunity.

Afiya is located in a residential neighborhood in Northampton, Massachusetts, and is central to a variety of community resources. It is available to anyone ages eighteen and older who is experiencing distress and feels they would benefit from being in a short-term, twenty-four-hour peer-supported environment with others who have 'been there.' Typical stays at Afiya range from one to seven days.

The majority of people you will meet (including in leadership roles) at Afiya identify as having lived experience that may
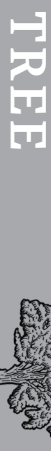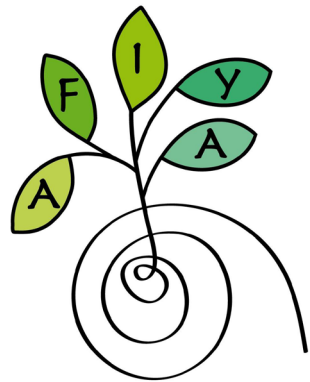
include extreme emotional or altered states, psychiatric diagnoses, trauma histories, living without a home, navigating the mental health, and other public systems, addictions and more. They have come together because they believe that the wisdom they have gained from their lived experience is invaluable and sharing their story has great potential to create connection and support for others on their own journeys."

A short video describing Afiya: **mindfreedom.org/afiya-house-video**

Second Story

Second Story is another example of a peer respite run by Encompass Community Services, a mental health agency based in Santa Cruz, California. It came perilously close to being shuttered in 2018 due to cuts in the mental health agency that runs it. An anonymous donor purchased the house and the agency, declaring that it supports the model is now searching for sustainable solutions. **mindfreedom.org/santa-cruz-second-story**
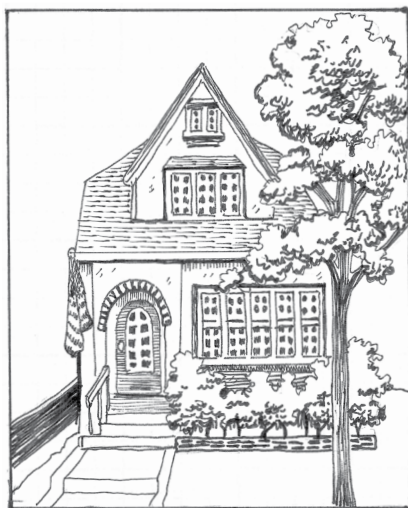
Second Story's website reads: "Second Story is a six-bed house which serves as a respite and a voluntary opportunity for individuals to learn to use relationships to move out of old roles and patterns. Staffed by 'peers,' (people with lived experience of mood swings, consuming fears, voices, visions, who have learned to be with some discomfort) the household provides an opportunity to experience what change feels like, and to learn new responses through relationships with each other. With the expectation that everyone is capable and inherently knows what they need, both paid staff and guests create a space for those qualities to surface. Along with creating a home, we share stories to connect and understand each other's experiences, gently challenging ourselves to listen to the untold story. The hope is not to rebuild a culture of illness,

TREE

but instead generate some sparkling moments of connection and trust, lessons which will spill over into the future.

Second Story is not a substitute for psychiatric hospitalization. Those who are drawn to the program develop, with staff, ahead of time, a plan for dealing with feelings and behaviors that in the past have led to inpatient stays. The first contact with staff is the beginning of using different views, working together to figure out what might be different. The summary of this meeting is kept on file until a time comes when a potential guest wants to stay at Second Story. The plan is updated and used as a guide to get good results from the time together at Second Story.

Second Story offers a maximum stay of 13 days in a home environment, and provides guests with opportunities to identify and plan for changes they feel will benefit them once they have returned home. All former guests are offered ongoing telephone support, and are welcome to visit when they need encouragement from their peers and Second Story staff. Program participants also have opportunities to enroll in Intentional Peer Support training and learn to be of assistance to others.

The start-up has been funded by a 2010 Federal Transformation award and is open to Santa Cruz County Mental Health clients 18 and over, who have housing, and have completed a proactive interview or first contact interview. For more information, call Second Story at (831) 466-0967."

Traditional system	Respite system
Clinically based relationships	Mutual growth based relationships
Illness oriented	Reframing/whole person
Problem based	Trauma informed
Symptom management	Being with and sharing experiences
Return to baseline	Transform how self is viewed
Continued management of symptoms	Acting on values and beliefs

A slideshow related to the history and principles adopted by Second Story: **mindfreedom.org/second-story-slideshow**

Supportive Research

One study with a control or comparison group, **mindfreedom.org/srstudy**, showed that respite guests at Second Story were 70 percent less likely to use inpatient or emergency services and that respite days were associated with significantly fewer inpatient and emergency service hours. Among individuals who used any inpatient or emergency services, a longer stay in respite was associated with fewer hours of inpatient and emergency service use. However, the association was one of diminishing returns, with negligible decreases predicted beyond fourteen respite days. Conclusions: By reducing the need for inpatient and emergency services for some individuals, peer respites may increase meaningful choices for recovery and decrease the behavioral health system's reliance on costly, coercive, and less person-centered modes of service delivery.

Characteristic	Respite (n=114)	Non-Respite (n=114)
Number of respite stays	2.3	-
Days spent in respite	29.8	-
Age, years	45.1	45.8
Female	48.2	46.5
Education, years	12.6	12.0
Age of first hospitalization, years	32.5	35.5
Voluntary legal status*	98.1	90.2
Has a care coordinator	76.3	78.1
GAF score	46.0	45.6
Schizophrenia diagnosis	41.2	52.8
Substance use diagnosis	14.9	15.8
Living in board and care*	3.4	12.6
Homeless*	2.2	9.5
Characteristic	**Respite (n=114)**	**Non-Respite (n=114)**
Number of respite stays	2.3	-
Days spent in respite	29.8	-

TREE

Items For Action

· **Find** the location of the nearest peer respite house where you live: **peerrespite.net/directory**

· **Download** and share the following handbook on how to launch and operate a peer respite in your community: **peerrespite.net/resources**

· **Form** a work group to read and discuss what it would take to launch and operate a peer respite house in your community. Consider inviting a wide variety of participants, including psychiatric survivors, peer specialists, mental health professionals, scientific allies, faculty members of nearby colleges and universities.

· **Plan** a town meeting in your community to discuss the need for alternatives to psychiatric interventions for people in crisis. Invite local leaders, especially people with lived experience, to speak publicly about their experiences in the mental health system and why alternatives are needed.

· **Invite** a representative from an existing peer respite house to present his or her findings.

· **Create** talking points using the resources in this chapter in the form of a flyer or brochure. Pass out at meetings and email or mail to lawmakers and policy makers.

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The Hearing Voices Movement

by John Herold, MA

After my release from a five-day involuntary hospitalization, I angrily expressed my dismay regarding my "treatment" to a friend over the phone, saying loudly and forcefully that someone ought to press charges against the hospital. I'll never forget her response.

"John, I can't talk to you when you're this manic."

Manic? I was righteously outraged from getting locked up, labeled, and drugged! It's not a mental illness to have a strong reaction to being violated. My rage felt justified, but because I had been labeled bipolar, any strong feelings I expressed were seen through the lens of that label. If I was sad, I was depressed. If I was angry, I must be manic.

What the hospital labeled a "manic episode" was a significant and special experience to me—but to my surprise, few people in my life seemed to agree. From the moment I entered the ER, I was viewed as sick, as somehow less human for entering an extreme state of mind. The assumption that I was mentally ill was widespread and felt impossible to fight.

I can admit that during this time in my life, there were aspects of my behavior and language that made little sense to most people. My abundant energy frightened friends and family. I held strange beliefs, stopped sleeping, and spent all my money. I appeared to be out of control. But there were also aspects of the experience that felt more like gifts than sickness. People around me couldn't hear the bells, but I heard them, and it was clear to me what they meant. Someone was telling me something important.

My encounter with an extreme state isn't something that can be wrapped up in a few words. It wasn't uniformly good or bad. Some parts were profoundly spiritual; others were kind of crazy. There were effects from antipsychotic drugs I found useful, and others that almost killed me. Sometimes viewing myself as sick gave me clarity, other times the concept of mental illness only made things worse. Professionals said they wanted me to be well, but they weren't interested in helping me make meaning.

And what does it mean to be well, anyway? So far, being well meant being sedated.

I longed for a community that would let me share and explore my experience using terms and concepts that felt best to me but was deeply discouraged by my community's offerings. Local support groups contained "bipolar disorder" and "mental illness" in their names. I had already been defined by diagnostic vocabulary in the hospital. I didn't need anyone else to speak for my experience.

There were aspects of psychiatric language that helped me identify patterns in my life, but the notion that my experience was only a disorder left me feeling powerless and empty. Sure, I acted crazy for a while, but is it a disorder to receive trusted messages from the universe?

And what about the unusual beliefs I expressed while so altered? Could there be value and meaning behind them? Was it merely a delusion to think I was the next Dalai Lama? Perhaps I didn't cure cancer in consensus reality, but did that mean I had to stop looking for the symbolic meaning behind that belief too?

There are many ways to understand extreme states of mind. Prescribers often view them as the result of some kind of chemical imbalance. Others believe such experiences are a response to emotional wounds. But what about the arrival of the bells and synchronicity in my life? Something felt deeply spiritual. Sometimes I wonder if this experience was something that just had to happen for the benefit of everyone. Each of these frameworks had something to offer. I needed the freedom to explore different paradigms without getting coerced into adopting any particular one, especially the notion that I was sick.

Discovering HVN

At the end of each episode of Will Hall's Madness Radio he says that the show is sponsored by an organization called Portland Hearing Voices. In early 2013 I reached out to Kate Hill, its director, hoping to learn more about their weekly meetings and overall philosophy. This phone call changed my life.

I told Kate the story of what I had been through the previous year. By this point, I had grown accustomed to being met with language of illness and disorders, as well as the belief that my experience wasn't meaningful. Kate had an entirely different response.

"Wow John. That sounds like an amazing experience. What does it mean to you?"

Kate's openness and curiosity were incredibly refreshing. She honored the reality of my experience and generously made space for me to unfold it using language that worked for me—a momentous turning point. Kate then invited me to an informal skills refresher for facilitators of Portland Hearing Voices the following day. I made the drive to Portland, the first of many trips.

Eight of us gathered in Kate's living room. We introduced ourselves, checked in, and briefly shared our stories. The diversity of attitudes and perspectives intrigued me. Some of us agreed with diagnostic labels; others didn't identify with them. Some of us took psychiatric drugs; others chose not to. Some embraced their experiences; others wanted theirs to go away. Every attitude, framework, and posture was welcome. Sharing was optional, people used plain language to describe their experiences, and we viewed one another as experts.

After sharing my story, I noticed less tension in my shoulders. For the first time in over a year, I sensed emotional safety. No one freaked out when I described my experience! No one said the bells, synchronicity, and unusual beliefs weren't real. No one told me I was sick. I felt mixed feelings at this new sensation. On the one hand, I had clearly found the group I was looking for. On the other hand, it became apparent just how deeply I had learned to silence myself.

I live with a variety of unusual experiences but rarely hear voices. Why then, would I attend Portland Hearing Voices? Because HVN groups aren't just for people who hear voices. The phrase "Hearing Voices" is an umbrella term—covering any unusual sensory experience including; voices, visions, extreme states of consciousness, unusual beliefs, tactile sensations, unshared realities, and more.

HVN groups are safe, open-minded, nonjudgmental spaces to share these experiences. Puget Sound Hearing Voices, the community-based HVN group I started in 2015, meets in a coffee shop every Tuesday night and is open to experiencers and their supporters. Some HVN groups take place in more restrictive settings like prisons and hospitals. I wish such a group had been offered when I was hospitalized.

What is HVN?

The Hearing Voices Network is a worldwide collaboration of people with lived experience, professionals, and supporters working to change assumptions and create understanding for people who live with unusual and extreme experiences. It is based largely on the work of social psychiatrist Dr. Marius Romme and his partner/research colleague Dr. Sandra Escher of the Netherlands. It was Marius's work with his voice-hearing patient Patsy Hage that created the foundation of HVN.

Patsy heard commanding voices and experienced great emotional distress. Marius wanted to help Patsy but was limited by his mainstream training that viewed her voices as hallucinations that were not real. Such thinking wasn't useful to Patsy, and she challenged Marius's attitude by asking a simple question. She asked if he believed in God, to which Marius confidently answered yes. Patsy then made an astute observation that would lead to the birth of a worldwide movement.

"Dr. Romme, you believe in a God you cannot see or hear. Yet I really do hear my voices, and you say they aren't real."

Marius considered these brilliant words and gradually realized the hypocrisy of his beliefs. Patsy's voices were real because she heard them. Instead of believing the only way forward was for Patsy's voices to disappear, he and Patsy explored their characteristics as well as her relationship with her voices; discovering meaning, purpose, and skills along the way.

Patsy and Marius appeared on a Dutch television show to tell the story of their work together. The host asked viewers with similar experiences to call in. They were overwhelmed with phone calls. The resulting interviews revealed a groundbreaking statistic: two-thirds of the callers who heard voices had no relationship with the mental health system at all. This discovery shows there are many possible relationships we can have with voices and other unusual and extreme experiences. Viewing them as mental illness is just one way.

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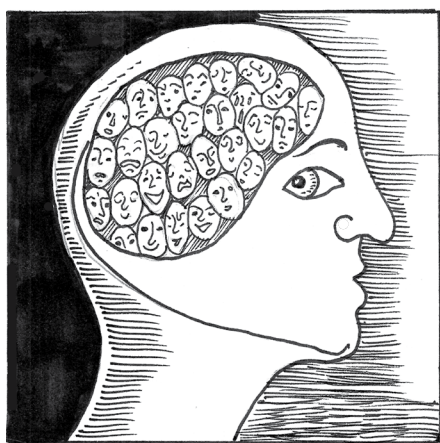
Marius also witnessed the power of peer support when he observed Patsy and other voice hearers exchanging ideas with one another. Marius realized experiencers—the real experts—could support each other better than he and his professional training ever could.

The first Hearing Voices groups were formed in the UK in 1988—and a worldwide movement was born. Hearing Voices Networks have been established in over twenty-six countries, arriving in the USA in 2010.

What Makes Hearing Voices Groups Different Than Other Support Groups?

HVN groups are committed to four important freedoms:

1.   We are free to interpret our experiences using whatever framework we choose.
2.   We are free to challenge social norms.
3.   We are free to change our minds at any time.
4.   We are free to talk about anything, not just voices and visions.

These freedoms make room for a wide diversity of attitudes, beliefs, and conversations. In HVN groups, no one will force you to view your

experiences through the lens of any particular label or disorder. Each of us has the right to use whatever vocabulary we choose for ourselves, including the diagnostic framework.

HVN also believes that there is nothing inherently wrong about voices, visions, and other unusual and extreme experiences. After all, some of our planet's greatest creative minds have been voice hearers. Instead, we ask, what do these experiences mean to you? Are you in distress? Help yourself to the collective support, expertise, and wisdom of the group. If you choose to share and receive feedback, you will receive it in a respectful and empathetic way.

While some support groups advise people to ignore their voices, HVN encourages building a more useful and beneficial relationship with them; one that gives you power, choice, and agency while reducing distress. We also believe there can be meaning behind these experiences, and that **the person who gets to decide that meaning is you.**

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How Do I Find a Group?

International
Intervoice is an International Network. If you live outside the United States or the UK, you can visit their website: intervoiceonline.org/about-voices and view a map: mindfreedom.org/intervoice-map of all the many countries with active Hearing Voices groups to find the one closest to your community.

United Kingdom
If you live in the United Kingdom, find a Hearing Voices group near you by viewing this map: mindfreedom.org/find-hearing-voices-group

United States

If you live in the United States, there are over 100 Hearing Voices groups on the map at the Hearing Voices Network USA website. Find one near you at **hearingvoicesusa.org.**

If there isn't a group in your local community, email **info@hearingvoicesusa.org** to get information about available online HVN groups. Or consider starting a group of your own!

Do I Need to Take a Training to Start a Group?

We strongly recommend taking a training before starting a group, but we understand that not all people will choose to wait for a training to become available. For this reason, HVN USA has developed a **Self-Reflection Tool:** **mindfreedom.org/self-reflection-tool** for individuals thinking about starting a group without training.

What are HVN Trainings Like?

In three-day Hearing Voices group facilitation trainings, participants learn the skills and tools needed to create, facilitate, and maintain HVN groups. We explore the history of the Consumer/Survivor/Ex-Patient Movement, coping and engagement strategies, the HVN Charter, facilitation techniques, difficult situations, and how to establish groups. We conduct exercises where nonvoice hearers get to experience what it's like to hear voices. We also ask big questions like, what is normal? Participants also get to share their experiences in a safe, nonjudgmental environment that closely resembles an actual HVN group.

HVN trainings are not just for learning to facilitate groups, though. Many participants find that the experience shifted how they view themselves. Some emerge using different language than before. These trainings are also an excellent way to meet others in the community who experience phenomena that fall under the umbrella of "Hearing Voices."

We encourage you to join this movement of liberation and self-empowerment, one that celebrates **mental diversity** instead of assuming mental illness.

Items for Action

Intervoice organizes an annual Hearing Voices Congress. View their website: **mindfreedom.org/hv-congress**

View and share the following educational resources with your friends:

· YouTube video of voice hearer, educator, and psychiatric survivos Rai Waddingham entitled *Working with Violent and Taboo Voices:* **mindfreedom.org/taboo-voices**

· Animation entitled *Compassion for Voices: A Tale of Courage and Hope:* **mindfreedom.org/compassion-for-voices**

· For children who hear voices, a good animation can be viewed at: **mindfreedom.org/kids-hear-voices**

· A *TED Talk* by Eleanor Longden, a psychiatric survivor, voice hearer, and therapist entitled *The Voices in My Head:* **mindfreedom.org/ted-voices**

· View and share the video entitled *Voices Matter* from the Open Paradigm Project at: **madinamerica.com/2013/05/voices-matter**

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Soteria House Model

"A non-medical, non-hospital, non-professional, home-like, minimal medication program for newly diagnosed psychotic persons . . . It is based on moral treatment principles and the tradition of intensive interpersonal intervention with psychosis. Research established that this program was as, or more effective than hospital based, medication dependent, professionally delivered treatment for this subject of psychotic persons."

–Loren R. Moshe, MD

History of Soteria

Soteria means "safety" and "deliverance" in Greek. It is the name generally used to denote a modern model of supporting individuals who are experiencing extreme states known as "psychosis" in homelike environments with minimal use of neuroleptics. This model was first proposed by Dr. Loren Mosher as an experiment. The first Soteria home was started in 1971.

Soteria House in Santa Clara, California

"The idea was to treat people as people, as human beings, with dignity and respect." —Dr. Loren Mosher

Dr. Mosher

Born and raised in California, Dr. Mosher received a BA from Stanford University and an MD with honors from Harvard Medical School in 1961, where he also subsequently took his psychiatric training.

Dr. Mosher was the first chief for Studies of Schizophrenia at the National Institute of Mental Health (NIMH) from 1969-1980. He was clinical cirector of Mental Health Services in San Diego, California, from 1996 to 1998. He founded the *Schizophrenia Bulletin.*

When Dr. Mosher died, psychiatric survivor and cofounder of MindFreedom, David Oaks, publicly declared, "Loren Mosher was like a Schindler of psychiatry as in the film, *Schindler's List.* One of the 'Schindler's has died." **moshersoteria.com/tributes/david-oaks-tribute**

When designing the Soteria experiment, Dr. Mosher stated, "This project's design was a random assignment, born from a two-year follow-up study comparing the Soteria method of treatment with 'usual' general hospital psychiatric ward interventions for persons newly diagnosed as having schizophrenia and deemed in need of hospitalization."

> "At the end of two years, the Soteria patients had 'lower psychopathology scores, fewer (hospital) readmissions, and better global adjustment' than those treated conventionally with drugs in a hospital setting. Only 31 percent of the patients treated without drugs in the Soteria House who remained off neuroleptics after leaving the program relapsed over the next two years." **madinamerica.com/2012/03/the-soteria-project**

The final report of this experiment can be downloaded and viewed from this downloadable PDF: **mindfreedom.org/soteria-report**

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The project first published systematic I-year outcome data in 1974 and 1975 (Mosher and Menn, 1974; Mosher et al., 1975). Despite the publication of consistently positive results (Mosher and Menn, 1978; Matthews et al., 1979) for this subgroup of newly diagnosed psychotic persons from the first cohort of subjects (1971- 1976), the Soteria Project ended in 1983. Because of administrative problems and lack of funding, data from the 1976-1983 cohort was not analyzed until 1992. Read more at: **mindfreedom.org/cohort-soteria**

Robert Whitaker describes the significance of these findings and the response it generated within the field of psychiatry:

"At the end of six weeks, psychotic symptoms in the Soteria patients had abated just as much as in the medicated patients. The home was effective as an acute care antipsychotic so to speak. Even more compelling, the Soteria patients were doing better at the end of two years. Their relapse rates were lower, and they were functioning better socially—more likely to be employed or attending school. In terms of their use of antipsychotics, 42 percent of the Soteria patients had never been exposed to antipsychotics at the end of two years; 39

percent had used the drugs temporarily; and 19 percent had used them continuously.

Although the results told of better long-term outcomes with this approach, the experiment was understandably seen as a threat to psychiatry, and the field's response came fast and furious. Mosher was accused of cooking his results, and while Mosher could easily refute the charge—he had independent investigators assess the outcomes, precisely to protect against this sort of accusation—the damage had been done. Funding for the project was soon shut down, even as an NIMH review committee, in a private written review, grudgingly admitted that the experiment had proven to be a success.

Not long after that, Mosher was ousted from his position as head of schizophrenia studies. Today, looking back, it is easy to see that this was a splitting-in-the-road moment for American psychiatry. Soteria became the path not taken, with Mosher's firing the equivalent of a danger sign placed at the head of the road." —Robert Whitaker, *Soteria Israel: A Vision from the Past is a Blueprint for the Future*": soteria.org.il/soteria-israel

Dr. Loren Mosher's Legacy

Dr. Mosher was heartbroken by the failure of the medical community to recognize the significance of his research and widely publish and learn from his findings. After his findings were shunned by the American Psychiatric Association (APA), he famously resigned from the APA. His letter of resignation: moshersoteria.com/articles/resignation-from-apa

View an interview of Dr. Mosher: mindfreedom.org/mosher-interview

The Soteria Model was not widely adopted in the US due to the domination of the medical model. Nevertheless, a resurgence of interest has caused states in the US and other countries to replicate the Soteria Model.

Soteria in the United Kingdom
soterianetwork.org.uk

Soteria Berne, Switzerland

Soteria Berne was founded in 1984 and is still operational. As with the original by Dr. Mosher, Soteria Berne was started as a research project conducted by Luc Ciompi. More information can be found at: ciompi.com/en/soteria.html

Soteria Israel

A Soteria home for men only opened in Jerusalem in the fall of 2016—the first house in a budding Soteria movement in Israel. A women's Soteria is also now operating in Jerusalem, and three more "stabilizing houses," which is the government's name for this model of care, have opened.

Writer Robert Whitaker visited the Soteria house for men, interviewing the founders and residents. His descriptions of what he observed and heard appeared in this *Mad in America* article: mindfreedom.org/soteria-israel

Role of Philanthropy

Dr. Mosher's original Soteria house depended entirely on funding from the National Institute of Mental Health (NIMH), which was abruptly withdrawn, ending the program completely.

Subsequent attempts in the US and elsewhere in the world to replicate the Soteria model faced many funding challenges. Future activists attempting to establish a Soteria house in their communities may need to rely on private philanthropic sources of funding.

Laszlo N. Tauber Family Foundation, a prominent mental health charity in Israel, has provided financial backing for the Soteria houses in Israel, and at a December 19 conference in Jerusalem, Sylvia Tessler-Lozowick, the foundation's director, set forth her vision for the future. "Soteria," she declared, "should be a first-line treatment" for people who have been newly labeled as "psychotic."

The Foundation for Excellence in Mental Health Care (FEMHC) is leveraging philanthropy to create program research around alternatives like the Soteria model. See more information about their work: mentalhealthexcellence.org

Soteria Alaska

Soteria Alaska was founded by Jim Gottstein in 2009. It operated for eight years, closing its doors in 2017. Jim Gottstein said that one challenge was "financial pressures." He states:

> "The authorities' insistence upon billing Medicaid as much as possible was always a problem. The idea of billing Medicaid, and the way that it is tied to disability, is contrary to the principles upon which Soteria was founded." madinamerica. com/2015/06/lessons-from-soteria-alaska

Another challenge was related to the population they served:

> "Soteria-Alaska also was fairly unable to receive first-episode, non-neuroleptized people for a couple of reasons. According to Susan (the first Executive Director of Soteria Alaska) and others, by the time people get to the age of 18, which is the youngest Soteria-Alaska could house, they had already been on neuroleptics for a number of years.. Soteria-Alaska was a tremendous help to many of these residents but, frankly, it is not designed as a withdrawal program for people who have been on neuroleptics."

Susan Musante, current board member of MindFreedom International, poignantly described the reasons that led her to serve as the executive director of Soteria Alaska for eight years: mindfreedom.org/soteria-alaska

Daniel Mackler, who served briefly as an interim executive director for Soteria Alaska while Susan was on sabbatical, describes in greater detail one of the challenges pointed out by Jim Gottstein:

> "The main area of drift from the vision is that Soteria-Alaska hasn't ended up working with the type of people for whom it was designed to help. Instead, for a variety of reasons, Soteria has worked almost exclusively with people who are more 'chronic' psychiatric patients, that is, people who, to varying degrees, have been in the psychiatric system for some time,

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have been exposed, in many cases for years, to psychiatric drugs (such as neuroleptics, mood stabilizers, antidepressants, and the like—and often combinations of them), have been psychiatrically hospitalized (sometimes multiple times), and may even be on government disability upon admission to the house. This is quite a departure from the original Soteria model, because compared with people experiencing a first psychotic break, 'chronic' patients generally have far more serious, intractable, and complex problems, and as the result tend to be far harder to help." —Daniel Mackler, *Mad in America:* **mindfreedom.org/observations-soteria-alaska**

Soteria Vermont

In 2015, a new small residential facility in Burlington, Vermont, called Soteria Vermont was established based on the principles of the original Soteria experiment by Dr. Mosher.

"The first of its kind in Vermont, Soteria is a five-bed mental health treatment facility that focuses on relationships— rather than medication—in a homelike environment. It isn't run by mental health professionals, and the doors aren't locked. There's a music room, a library, a space for arts and crafts, and a garden. Aside from mealtimes, days at the Soteria Vermont house are unstructured; residents are free to walk the neighborhood, shop or attend classes."

–Nancy Remsen

mindfreedom.org/seven-days-soteria-vermont

Here is how Soteria Vermont describes their program on its website (**mindfreedom.org/pathways-vermont**):

> "Soteria is a Therapeutic Community Residence for the prevention of hospitalization for individuals experiencing a distressing extreme state, commonly referred to as psychosis. We believe that psychosis can be a temporary experience that one works through rather than a chronic mental illness that needs to be managed.
>
> We practice the approach of 'being with'—this is a process of actively staying present with people and learning about their experiences. Soteria believes in the power of each individual's wisdom and intuition and we believe that strong relationships provide opportunities for powerful transformation."

Soteria Vermont provides:

- A safe, non-restrictive, home-like environment.
- Flexible, non-judgmental, person-centered services.
- Specialized, inter personally-driven support.
- 24-hour staffing.
- Coordination with community services providers and other resources, such as housing, education and employment assistance.
- Six months of aftercare support.
- Optional psychiatric consultation.

View video of Soteria Vermont: **mindfreedom.org/soteria-video**

Soteria Vermont makes a compelling argument that more alternatives to forced psychiatric care are needed if only for cost effectiveness.

On their website, Soteria Vermont states:

> "Psychosis is considered to be one of the most expensive mental health conditions. Frequent and long-term hospitalizations combined with high rates of disability among individuals diagnosed with a psychotic disorder carries a high price tag."

VERMONT PSYCHIATRIC CARE HOSPITAL: $1,862

SOTERIA: $547

COST COMPARISON OF A PERSON STAYING AT SOTERIA VERMONT V.S. THE VERMONT PSYCHIATRIC CARE HOSPITAL

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0          $500         $1000        $1500        $2000
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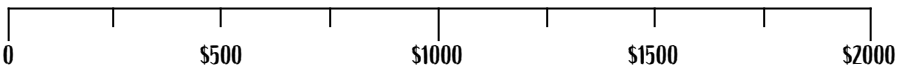
They also claim that the cost of supporting individuals in a homelike environment through Soteria Vermont is a fraction of what it would take to treat the same individuals in an acute hospital setting: **mindfreedom. org/soteria-cost**

Resources

For scientific data supporting the Soteria model, check out these resources:

"A Systematic Review of the Soteria Paradigm for the Treatment of People Diagnosed With Schizophrenia" by Tim Calton in *Schizophrenia Bulletin:* **mindfreedom.org/soteria-data**

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Items for Action

· View and share a taped interview of Dr. Loren Mosher: **mindfreedom.org/mosher-interview**

· Consider organizing a public screening of this interview at your local church, school, mental health agency, peer organization, etc.

· View and share a webinar entitle: *"Voices for Choices: Organizing for Alternatives to Forced Psychiatric Treatment."* Hilary Melton, executive director of Soteria Vermont is one of three featured presenters. Webinar: **mindfreedom.org/voices-for-choices**

· Read the book entitled **Soteria: Through Madness to Deliverance** authored by Dr. Loren Mosher and Voyce Hendrix, with Deborah C. Fort as a collaborator.

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Open Dialogue

"As living persons we are relational beings . . . Nothing more is needed than being heard and taken seriously . . . the challenge in any kind of psychological help is to give up our own aims to produce change in our clients through our interventions. As professionals we should learn to follow the way of life of our clients and their language—entirely, without preconditions."

–Jaakko Seikkula

Open Dialogue is the mental health system of care delivery practiced, even to this day, in Western Lapland since the 1980s. At that time, Jaakko Seikkula was a psychologist at the University of Jyväskylä, charged with heading up trainings for staff at Keropudas Hospital in Tornio, Finland. Together with Birgitta Alakare, Jukka Aaltonen, and many others, Seikkula developed ways that the entire mental health care delivery system could all work together. These became named the seven principles of Open Dialogue which, according to long-term research, have led to consistent findings.

Recent nineteen-year studies, and others in prior studies, have shown that these practices reduced hospitalizations, neuroleptic use, disability, and unemployment. Interdisciplinary staff flexibly adapted to the needs of clients, assisting people in mobilizing their own resources to deal with mental health challenges, maintaining consistent treatment teams to each corresponding crisis, for as long as the client, and family/social network felt it was needed.
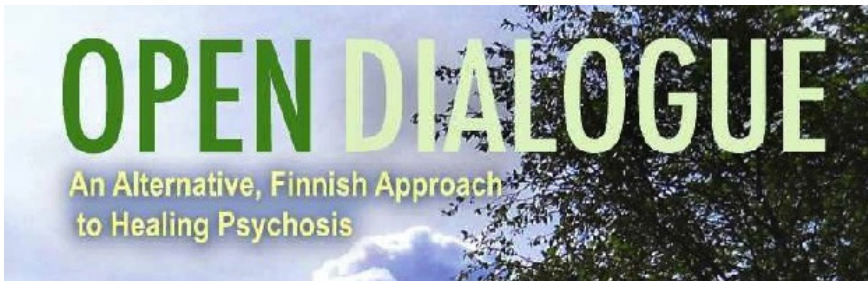
This small area of Finland has consistently demonstrated the best documented recovery outcomes in the Western world for "schizophrenia" or "psychosis."' Read the entire study at: mindfreedom.org/open-dialogue-facts

· According to a five-year follow-up study (Seikkula et al. 2006), 83 percent of patients have returned to their jobs or studies or were job seeking, thus not receiving government disability. In the same study, 77 percent did not have residual psychotic symptoms.

· The Open Dialogue patients were hospitalized less frequently, and three percent of these patients required neuroleptic drugs, in contrast to 100 percent of the patients in the comparison group.

· At the two-year follow-up, 82 percent had no, or only mild non-visible psychotic symptoms compared to 50 percent in the comparison group.

· Patients in the Western Lapland site had better employment status, with 23 percent living on disability allowance compared to 57 percent in the comparison group.

· Relapses occurred in 24 percent of the Open Dialogue cases compared to 71 percent in the comparison group *(Seikkula et al., 2003).*

Open Dialogue received increased attention in the US after Robert Whitaker included it as a promising replacement for standard crisis oriented approaches in **Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America.** Today, Open Dialogue is an emerging and promising practice in the US.

It is a comprehensive clinical approach quite different than what is offered in the US. Indeed, even in Finland, where it originated, it is only practiced in the northern half of Finland. Many other countries, however, are participating in research to further the implementation of Open Dialogue, including Italy, the UK, Germany, the Netherlands, and others.

Some of the components of Open Dialogue include:

- · Working in teams/doing co-therapy as a standard of practice.
- · Treatment that opts for taking place in a person's home. (This tendency originated from an attitude of helping families and communities resource their own ways, not assuming the hospital or professionals had "answers," but that they would come to them, share responsibility, in sufficient time, exploring options and sitting in the process of uncertain outcomes.)
- · Quick and consistent response time when help is asked for.
- · Emphasis is on creating a safe and expansive space (plenty of time) between people in their social and family network to express themselves. Therapists reflect as real human beings, slowly, without implementation or assumption of answers, but rather with embodied curiosity.
- · Shared responsibility. No one is told they need to call another place when help is asked for. Help is always organized as quickly as possible, in flexible ways utilizing many types of professionals.
- · It incorporates multiple clinicians/disciplines and perspectives including people from the individual's family/friend support system in the community.
- · Treatment-planning does not take place separate from the therapy sessions themselves. All clients and family are witness to and participatory in the whole treatment process.
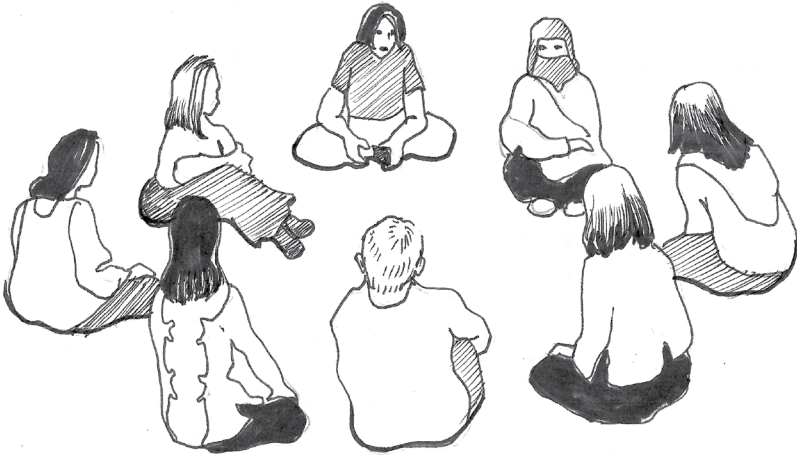
Seven Principles of Open Dialogue:

1. IMMEDIATE HELP

- First meeting aimed to take place within twenty-four hours
- All participate from the outset
- "Psychotic" stories are discussed openly with everyone present
- The patient reaches something of the "not-yet-said"

2. SOCIAL NETWORK PERSPECTIVE

- Those who define the problem should be included into the treatment process
- Joint discussions regarding decisions on who knows about the problem, who could help, and who should be invited into the treatment meeting
- Family, relatives, friends, fellow workers and other authorities

3. FLEXIBILITY AND MOBILITY

- The response is need-adapted to fit the changing needs of every patient and their social network
- The place for the meeting is jointly decided
- From institutions to homes, to working places, to schools, to polyclinics, etc.

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4. RESPONSIBILITY

· The one who is first contacted is responsible for arranging the first meeting

· The team takes charge of the whole process regardless of the place of the treatment

· All issues are openly discussed between the doctor in charge and the team

5. PSYCHOLOGICAL CONTINUITY

· An integrated team, including both outpatient and inpatient staff, is formed

· The meetings happen as often as needed

· The meetings occur for as long a period as needed

· The same team both in the hospital and in the outpatient setting

· In the next crisis the core of the same team

· Not to refer to another place

6. TOLERANCE OF UNCERTAINTY

· To build up a scene for a safe enough process

· To promote the psychological resources of the patient and those nearest him/her

· To avoid premature decisions and treatment plans

· Slow to diagnose, prescribe outcomes, waiting for more voices to emerge

7. DIALOGISM

· The emphasis is generating dialogue—not primarily in promoting change in the patient or in the family

· New words and joint language for the experiences, which do not yet have words or language

· Listen to what the people say not to what they mean

In addition, there are twelve key elements. Researchers Doug Ziedonis, MD, Mary Olson, PhD, and Jaakko Seikkula, PhD, together published these as fidelity criteria, so as to easily begin adopting the way to work this way, particularly also to more easily design studies in the future. There have been studies applying Open Dialogue at University of Massachusetts, Emory University, and University of California at San Diego. Currently worldwide studies are being conducted in Belgium, Italy, United Kingdom, and ongoing research in Finland.

The following article was written as a guest post on Monica Cassini's blog. It is reprinted here with permission: **mindfreedom.org/finnish-dialogue**

My Reflections on the Finnish Open Dialogue Project

by Daniel Mackler

In June of 2010, I visited Western Lapland in Finland for two weeks. My goal was to make a documentary film on the Open Dialogue project. Although the film is now complete, and I feel it tells their story fairly well, there remains a lot that I left out—things I somehow, for one reason or another, couldn't capture on camera.

I want to share a few of those missing things here. I first want to share my impressions of arriving at the Keropudas Hospital in Tornio, Finland, which is the nerve center for Finnish Open Dialogue. It all began there, almost thirty years ago. I actually stayed on the hospital grounds for my two weeks in northern Finland, so I had a lot of time to spend wandering around the hospital, talking with patients, and just watching how life unfolded on a day-to-day basis, and in the evenings too. Because

TREE

of the Finnish confidentiality rules, however, I was not allowed to film patients—which was very disappointing and frustrating for me—but the administrators did let me talk with whomever I wanted, ask whatever questions I wished, walk freely inside the hospital without a pass or escort, and even visit their locked ward whenever I wanted, which I did often. Oddly, no one seemed to mind what I did there, or where I went—they really let me go free. I also sat in on many Open Dialogue therapy sessions, which, again unfortunately, I couldn't film, but I did come away with impressions. Many.

Meanwhile, my first impression of arriving at the hospital: it was shocking. The reason: the first people I saw when I arrived at the hospital were several—maybe six or eight—very troubled looking, middle-aged or elderly men and women shuffling around outside the hospital entrance and inside the hospital lobby looking quite drugged, and some seeming to be experiencing serious long-term neurological side-effects from antipsychotic drugs. Also, some were mumbling to themselves, and a few immediately recognized me as a new visitor, approached me, and begged for cigarettes.

What shocked me was that I had trouble believing that this was Open Dialogue, the place supposedly getting the best results in the world for the treatment of psychosis. To be frank, this looked like one of the worst hospitals I'd ever been to!

Interestingly, I'd come to Finland armed with questions and criticisms, and ready to really "get to the bottom" of Open Dialogue—to find out, at some level of confidence for myself, if they were really any good, or if their great results and reputation were really all a fantasy. But I certainly wasn't expecting this. I thought I was going to have to dig, and dig hard. Instead I found the criticisms right on the surface.

Meanwhile, I talked with several of these patients—in their broken English, as I spoke no Finnish (except for the word "neuroleptic," that is, "antipsychotic," which sounds similar in

TREE

Finnish). I shared a few cigarettes, and found them friendly, but still, quite disabled, presumably by the drugs.

What I found out later, however, was fascinating, and quite the opposite of my first impression. These folks had been long-term hospital patients at Keropudas Hospital back from the days prior to Open Dialogue. Some of them had been around since the 1970s—back when Western Lapland, I have since been told, was getting some of the worst outcomes for schizophrenia in Europe, back when there was no Open Dialogue, and back when everyone with issues labeled as psychotic was getting heavily medicated. These folks I met were the people who didn't recover—and hadn't been able to integrate living in the community. These were the people labeled as "failures" of a failing and quite traditional psychiatric system.

I also learned that in recent years, since the development of Open Dialogue, the therapists and psychiatrists had tried, sometimes several times with different people, to help these long-term patients taper off their neuroleptics, with often terrible results. They simply were too neurologically impaired by the drugs themselves, over too many decades, to be able to get off them. So presently they were on the lowest doses they could tolerate.

That was the first point: that these people were actually no reflection whatsoever on the success of Open Dialogue, but instead reflected the horror of the previous system. But over

TREE

time, when I thought about it more, I actually learned that they were a reflection on the Open Dialogue system, in some key ways. First, they were not kept on locked wards. They could come and go as they pleased. They were not confined. This was their home, and they actually had a lot of freedom in it. Second, I talked with many of them more over the subsequent two weeks, and many said they liked it here—because people were kind, because they felt respected, and because they felt safe and secure.

Also, I realized that for a short-time visitor, someone who only came for a day or two, who couldn't get a chance to explore the significance and history of these people who were a product of the old system, these folks risked being, in a way, terrible public relations for the Open Dialogue system. Had I only visited Western Lapland for the day, I would have been left with the impression that these neurologically damaged people were the face of Open Dialogue. Certainly the Open Dialogue clinicians recognized this too, and recognized that these people were the first people their many visitors met when they arrived! (And they get a lot of visitors. For example, there were eighteen Danish clinicians visiting the day I arrived.) And yet they did nothing to hide them, or to warn people about them, as I suspect many other programs might do, for political or promotional reasons. These folks were as welcome there as anyone else—welcome to interact with you or me, welcome to ask for cigarettes, welcome to talk, welcome to hang out and do whatever they wanted. I became quite friendly with several of them over my two weeks there. And we shared a lot of smokes.

Doing a little digging, I asked the clinicians if they felt any motivation to keep these folks out of the public eye, and they looked at me horrified. "Why would we do that?" they replied. "They have as much right to be here as anyone else!"

I smiled. I agreed.

A second key thing I learned about Keropudas Hospital, which,

like most mental hospitals, is placed on the far outskirts of town (in their case, on the edge of the forest), is that it's a rather large hospital that is relatively unused. There are one or more whole wards that are unused. I remember visiting one. It looked like an average, spacious hospital unit, but it was silent—and empty. It was dusty. Nothing was happening there. And the reason: they no longer have patients for them. They've developed such an effective system of helping people get well from psychosis, and get permanently out of the psychiatric system, that they no longer need so many beds. (No wonder they have some of the lowest per capita spending for psychosis anywhere in Finland— at least that's what I've heard. When people get fully well, and are able to get off all their psychiatric drugs, they save the system a lot of money.)

Also, much of the work they do helping people with psychosis, most of it, in fact, has nothing to do with the hospital itself. In most cases they don't prefer that people in crisis come to the hospital, and they don't even do much therapy in the outpatient clinic that is located at the hospital. In fact, their hospital outpatient clinic has only one therapy room—one therapy room to serve a population of around 70,000 people!

Granted, the Open Dialogue clinicians do have an outpatient therapy clinic in each of their catchment area's two largest towns (Tornio and Kemi), but they even prefer to avoid using these clinics for therapy, if at all possible. Their best preference is to meet in people's homes. The therapists, usually a team of two or three trained family therapists, travel to the homes of the people in crisis. The clinicians made a point of telling me repeatedly that they saw no value in having people come to the hospital for therapy, because of the stigma. They felt that if they could help people get better at home, in their natural environment, then it was all for the good. Also, the clinicians told me repeatedly that they learned far more from people by seeing them in their homes than they could ever learn by seeing them in such an artificial place as a hospital or clinic.

So, although some of what I'm writing overlaps with the content of my film, I feel this is important enough to bear repeating. In two weeks of staying in Western Lapland, I really came to believe that this program is what it claims to be: a program that helps a lot—a lot—of people get well from psychosis, without meds. Although in one sense I gained this belief by talking with clinicians, who said things that people who have never watched someone go through the process of recovery (or who hadn't lived it themselves) could have known, I gained it more from talking to the people they worked with.

As I said, I sat in on many Open Dialogue sessions, and although they were mostly in Finnish (sometimes, when the people coming for help felt comfortable, they adjusted and spoke in English for me), I still was able to gather a surprising lot—about their openness, their humanity, and their respect. Also, sitting in the sessions gave me an entrée to talk afterward with the people coming for help, the so-called clients and their families. One thing that struck me profoundly, even in really complicated and sticky emotional situations—situations that would have ended up with someone getting heavy medicated almost everywhere in the United States, but weren't ending up that way here—was that I didn't meet a single person seeking psychiatric help here who was bitter, or even unhappy, about the treatment they were getting. In fact, I didn't find "treatment" to be a dirty word in Western Lapland. Nor was "psychiatry." That struck me as bizarre, because for me both of those words have an inherent

TREE

dirtiness for me, the second especially. And that's entirely because of my own experience with each, both personal and professional.

What I heard from the Finnish people seeking help was that they felt the Open Dialogue system was fair—and honest. They also told me repeatedly that it felt "normal" to them. They used those words repeatedly. Interestingly, most of them seemed to have no idea that psychiatry was commonly hated and mistrusted in many other parts of the world, and even in parts of their own country. In fact, when I explained this to them many were genuinely surprised, as it contradicted their experience. This led them to tell me other things they liked best about their system. And they liked many things.

They liked the openness and frankness of the therapists. They liked it that above all else their own voices were heard and valued. They liked it that they had a key say in the decision about whether or not psychiatric drugs might be of benefit to them or not. They liked it that they had alternative options to drugs presented to them. They liked it that when they were in crisis they could invite their family and friends and other important people from their lives into therapy meetings—if they wished.

They also liked it that the therapists worked in teams, right in session—because they liked listening to what the therapists had to say to each other, in the middle of session. They told me that they felt they deserved to know what the therapists were thinking! And doesn't it make logical sense?

They also told me that they liked it that their therapists met with them immediately in their crises, and didn't put them off for months on endless, bureaucratic waiting lists. They liked it that therapists gave them the choice of meeting in their own homes or in clinics. They liked it that hospitalization was only used in cases of dire safety issues, and that hospitalizations were generally quite short. And they also liked it that visitors like me

TREE

were so interested in what was going on with Open Dialogue—and were also interested in their lives. Many of them wanted to know what I myself thought of their lives, their situations, and of their therapy too. And, because it was Open Dialogue, and because I felt safe there, I shared my opinion. And they valued it. And it even felt therapeutic—which felt good to me.

One young Finnish man, who, along with his family, sought help in an emotional crisis, shared something interesting with me after I asked him what he thought of their Open Dialogue psychiatric system. He replied, "Well, it's kind of like the town's water-works—they do a good job. When you turn on the faucet in your kitchen sink, you know that good, clean water comes out and you can drink it or cook with it. You trust that it will work, and that you won't get sick from the water. It's the same with psychiatry here—we trust them. When we have problems, we go to them. They are reliable, they care about us, and they do a good job. They help us. They make our lives better. It's just normal. But really, we don't think about it too much. Mostly, it's really just like the water-works—we expect it to work, and it does." More about Daniel at: wildtruth.net

Open Dialogue trailer: mindfreedom.org/open-dialogue-trailer

One individual in a forum sponsored by Open Dialogue asked the following question:

"In the Harrow study (2014, p.4, Fig. 3) 93 percent of people diagnosed with schizophrenia who had never taken a neuroleptic had ceased to be psychotic after 4 years. They could have other problems, but at least the psychosis was behind them. This rate is apparently better than that of the Open Dialogue.

This suggests that the results of the Open Dialogue could be explained more by what it does not do, and less by what it does. In particular, the reduction of neuroleptic consumption, the decrease in the number of hospitalizations, etc.

It is likely that the effectiveness of the Open Dialogue is largely a matter of doing nothing, except talking, not taking a harmful step, and waiting for the psychosis to end."

Challenges in Importing Open Dialogue

Alita Taylor, MA, is a Licensed Marriage and Family Therapist and an Open Dialogue trainer and supervisor living in Tacoma, Washington, with her partner Fletcher Taylor, MD, a psychiatrist. The two of them conduct Open Dialogue "network meetings" with clients and their supporters at a private clinic in Tacoma. Alita is very committed to Open Dialogue and claims "dialogue is medicine." She states that Open Dialogue is an example of applied science. It is an evidentiary method that utilizes up-to-date medical scientific findings, for instance, in the field of Interpersonal Neurobiology, the work of psychiatrist and scientist Dan Siegel, MD, has called the brain "a social organ." We are capable, in relationship, to find infinite responses to difficult situations. Open Dialogue provides a space for the relationships that matter most in our lives to grow, to create new meaning and directions together. Within the "in-between" space, in embodied relational dialogue, possibilities are endless.

Alita describes the challenges of conducting network meetings in the US. Currently, there are no billing codes in existence for network meetings which are the crux of Open Dialogue treatment. If there were, it would make it possible for mental health professionals who are trained in Open Dialogue such as counselors, social workers, nurses, and psychiatrists to receive sufficient reimbursement. Insurance companies and practitioners who bill insurance are regulated to abide by long-dictated Medicare guidelines/CPT procedure codes for payment. Currently, Alita and her partner can only afford to conduct network meetings benefiting two to four clients/families at their clinic in Tacoma. Fletcher, in describing the institutional barriers they face, says, "In reality, we have two clients: (1) each client/family, and (2) the instituted mental health structure for treatment delivery set up in the US. currently, and we know which one is going to be the easier of the two to treat."

One thing we can do is to approach our local mental health agencies at the county level. Consider how crisis and ongoing funding can merge. Ask, from the onset when someone calls for help: How can a team (social worker, doctor, and peer professional, for example) be formed and respond within 24 hours with that same team following that same client and family/social network? How could the expectation be set that that person needing help not lose the services just when they're getting started and trust is built with that first practitioner team?

Often at the local level, decisions can be made to write codes for treatment, so many local health care authorities could save money in the long term, if they examine the Open Dialogue outcome studies, and commit to sufficient training, response, and follow-up, regardless of diagnostic/assessment level of care criteria defined by past models. The teams would not change if the client needed intermittent hospitalization, residential treatment or intensive outpatient treatment. The network meetings continue taking place with the same team no matter where the client is. In addition, health insurance companies often bid for county mental health contracts. These insurance companies manage payment for client services and might be very keen to partner in approaches that bring pharmacy cost savings, less hospital costs, and good patient care.

Alita says: "Dialogue is needed most of all. The worst way to begin re-shaping our mental health care services is to blame one another. We need to listen. We can utilize the wealth of experience of practitioners in the mental health field now, and learn from the experiences of those who have had treatment failures in the way we have been doing things.

- What would have been helpful?
- Who are the helpers now?
- How do we create conversations that move toward openness?
- Many practitioners fight burnout, feeling themselves that the system in which they are trying to practice is broken.
- We need to admit mistakes and create talking spaces to reflect on what can change.
- We need to avoid "knowing the answer."

· We need to steer clear of making manuals and steer toward listening to one another's experiences and perspectives.

· We need to trust in the words people say and witness the thoughts, feelings, and expressions people have.

Listening and tolerating uncertainty is not easy, but it actually can be quite simple."

> "It's worth repeating, that the biggest bonus points Open Dialogue gets in the eyes of stakeholders in health care insurance companies, hospitals, social service programs, and taxpayers, is that Open Dialogue saves money. Patients in crisis, and their families, get immediate ongoing care with a consistent team of mental health professionals, who they gain trust with over time, and with commitment on behalf of the mental health service system, and subsequently, the research shows, less chronicity develops, which means less unemployment, less institutionalizations, less disability allowances, and less long-term neuroleptic costs."

Practitioners of Open Dialogue are receiving calls from people in distress who want this service in their community. These services are not widely available and very few people who could benefit from Open Dialogue are able to access Open Dialogue services. Open Dialogue trainings are now offered to clinical and peer professionals: **opendialoguewashington.com/foundation-training**

TREE

Open Dialogue Washington

Foundation Training commencing in April 2019

with Nick Putman and Alita Markus

Agencies can bring this training in-house (into their own agency without traveling to Tacoma or Finland. There are over 76 trainers worldwide and more up and coming who can organize themselves to train agencies in Open Dialogue.

Open Dialogue Studies and Other Resources

Studies

A North–South Dialogue on Open Dialogues in Finland: The Challenges and the Resonances of Clinical Practice—Australian and New Zealand Journal of Family Therapy: mindfreedom.org/ns-dialogue

Theory, practice and use of self in the open dialogues approach to family therapy: A simple complexity or a complex simplicity? mindfreedom.org/family-therapy

Nineteen year outcomes of Open Dialogue: mindfreedom.org/family-oriented-open-dialogue

Information

· Open Dialogue (International): open-dialogue.net
· United Kingdom: opendialogueapproach.co.uk
· General Information from MindFreedom: mindfreedom.org/kb/finland-open-dialogue
· Belgium: mindfreedom.org/open-dialogue-belgium
· France: mindfreedom.org/open-dialogue-france-fb-group
· New York City: mindfreedom.org/open-dialogue-newyork
· Washington state, USA: Open Dialogue Washington facebook.com/opendialoguewashington

Training Resources in the United States:

· Institute for Dialogic Practices: dialogicpractice.net
· Open Dialogue Washington Foundation Training: opendialoguewashington.com/foundation-training

TREE

Items for Action

What small steps can you take to bring Open Dialogue to your community?

1. Share evidence of Open Dialogue as a cost-saving and effective approach, especially to policy makers and lawmakers. (See studies.)

2. Encourage health care practitioners in our lives to get trained in Open Dialogue so that as policy changes there will be those available to provide the service to those in need.

3. Invite a trained Open Dialogue practitioner to give a presentation to stakeholders in your community. Do you have special access to one of the following potential sponsors/audiences?

   · Community Mental Health Agencies

   · Legislative caucuses or workgroups that deal with mental health

   · State Health Authorities

   · PAIMI Advisory Councils

   · Centers for Independent Living

   · State Disability Rights organizations

   · City councils and county advisory boards

   · Consumer/Survivor Advisory Boards

   · Office of Consumer Affairs in your state

   · Churches

   · Public safety/police oversight committees

   · Human Rights organizations and other nonprofits

TREE

Resources to Share with Groups

View **Open Dialogue: An Alternative Finnish Approach to Healing Psychosis**
mindfreedom.org/open-dialogue-trailer

Listen to an interview by Will Hall entitled *Open Dialogue for Psychosis with Mary Olson from Madness Radio.* mindfreedom.org/madness-radio-open-dialogue

Purchase a film about Open Dialogue by Daniel Mackler
mindfreedom.org/open-dialogue-daniel-mackler

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GROVE

This section is dedicated to the wealth of knowledge learned by pioneers in the psychiatric survivor's movement. It is about how this movement intersects with other movements for social change, and it includes tactics and strategies for effective activism.

GROVE

Disability Rights Movement

It took years for the milestones of the Disability movement to be achieved. For decades, activists advocated for the removal of barriers so that people with disabilities could participate fully in society. This advocacy has often taken the form of civil disobedience described below.

Milestones

1975   The US Supreme Court, in **O'Connor v. Donaldson**, rules that people cannot be institutionalized against their will in a psychiatric hospital unless they are determined to be a threat to themselves or to others. It is a violation of civil rights to medicate, treat, or hospitalize a person against their will.

1977   **National Institute of Mental Health (NIMH)** initiates a unique but modestly funded demonstration program, the Community Support Program (CSP), to stimulate and assist states and localities in improving opportunities and services in the community for people with a serious mental illness.

1977   US Congress creates a **National Committee for the Protection of Human Subjects of Biomedical and Behavioral Research** to investigate allegations that psychosurgery—including lobotomy techniques—are used to control minorities and restrain individual rights.

1978   Amendments to the **Rehabilitation Act**: provides for consumer-controlled centers for independent living.

1978   On July 5-6, 1978, Wade Blank, founder of **ADAPT** (1983), and nineteen disabled activists hold a public transit bus "hostage" on the corner of Broadway and Colfax in Denver, Colorado. ADAPT (originally Americans Disabled for Accessible Public Transit and later in 1990, Americans

Disabled for Attendant Programs Today) eventually mushrooms into the nation's first grassroots disability rights activist organization. They use sledgehammers to create the first curb cuts for wheelchairs in the country.

1980   Congress passes the **Civil Rights of Institutionalized Persons Act (CRIPA)**, authorizing the US Justice Department to file civil suits on behalf of residents of institutions whose rights are being violated.

1985   **Mental Illness Bill of Rights Act**: requires protection and advocacy services (P&A) for people with mental illness.

1986   Following numerous reports of abuse and neglect in state psychiatric hospitals and inadequate safeguards of patient rights, Congress passes the **Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act of 1986** (P.L. 99-319; 42 U.S.C. 10801 et seq). This act is modeled after the Developmentally Disabled (DD) Act and extends similar protections to persons with mental illness who reside in facilities. The act is designed to set up protection and advocacy agencies for people who are inpatients or residents of mental health facilities.

1987   Justin Dart, commissioner of the **Rehabilitation Services Administration**, is forced to resign after he testifies to Congress that "an inflexible federal system, like the society it represents, still contains a significant portion of individuals who have not yet overcome obsolete, paternalistic attitudes toward disability . . ."

1988   **Housing Amendments Act**: prohibits discrimination in housing against people with disabilities and families with children.

1988   **Civil Rights Restoration Act**: counteracts bad case law by clarifying Congress's original intention that under the Rehabilitation Act, discrimination in ANY program or service that is a part of an entity receiving federal funding—not just the part which directly receives the funding—is illegal. Congress overrides President Ronald Reagan's veto of this legislation.

GROVE

1988   The original version of the **Americans with Disabilities Act (ADA)** is introduced to Congress.

1990   The **ADA is signed by President George Bush** on July 26. It protects the civil rights of people with disabilities and gives some protection to people diagnosed with mental illness by stating, "services and supports must be provided in the most integrated setting appropriate to the individual," thus advocating for community placement for people. Closely modeled after the Civil Rights Act and Section 504, the law is the most sweeping disability rights legislation in history. It mandates that local, state, and federal governments and programs be accessible, that businesses with more than fifteen employees make "reasonable accommodations" for disabled workers, and that public accommodations such as restaurants and stores make "reasonable modifications" to ensure access for disabled members of the public. The act also mandates access in public transportation, communication, and in other areas of public life.

1992   **"The Independent Living Movement and people with psychiatric disabilities: Taking back control over our own lives."** *Psychosocial Rehabilitation Journal,* 15, 3-19. Deegan, P.

1992   **Reauthorization of the Rehabilitation Act**: provides for greater consumer control through the development of Statewide Independent Living Councils (SILCs). Title I presumption of eligibility and sixty-day eligibility determination period. Amendments to the Rehabilitation Act are infused with the philosophy of independent living.

A detailed timeline of disability rights can be found at: **mindfreedom. org/ada-timeline**

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TITLE II
"No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by such an entity."

(Pub. L. 101–336, title II, § 202, July 26, 1990, 104 Stat. 337.)

Direct Protests

Members of the Disability Rights Movement have been involved in "boycotts, blocking traffic, protest marches, and sit-ins. All of these protests closely mirror the tactics used in the broader Civil Rights Movement and with much of the same success. Protests bring about awareness of a problem to the wider community—in this case, the injustices and unfair treatment of people with disabilities.

On Monday, March 12, 1990, disability rights activists descended on the US Capitol demanding the passage of the Americans with Disabilities Act (ADA), which would give equal rights to people with disabilities. The ADA had passed by the Senate the year before but not through the House of Representatives. Over 1,000 protestors came from thirty states to protest the act's delay. After the day's rally and speeches, over sixty activists abandoned their wheelchairs and mobility devices and began crawling up the eighty-three stone steps to the US Capitol Building.

As she was inching her way to the top, activist Paulette Patterson stated: "I want to be treated like a human being." Eight-year-old Jennifer Keelan was famously taped while crawling up the stairs. "I'll take all night if I

GROVE

have to," she firmly stated. The second-grader from Denver suffered from cerebral palsy and decided to partake in the crawl after joining ADAPT (Americans Disabled for Accessible Public Transit).

Yoshiko and Justin Dart lead a march

The Capitol Crawl is seen as one of the single most important events that finally pushed for the passage of the ADA into law. The rights under the ADA are summarized by the Department of Justice: **ada.gov/cguide.pdf**

Litigation

Legislation is considered by most activists to be the crown jewel of all organizing. But legislation alone is not enough to protect people's rights. If mandates are not enforced, they are meaningless words on paper. Litigation is another important way that activists enforce civil rights.

Employers, government agencies, public transportation providers, etc. that are not compliant with the ADA may be sued. A plaintiff is a person or group of people bringing a complaint against a party, usually with the assistance of an attorney.

Activists crawling up the steps at the United States Capitol

Rulings in the lower courts can be appealed to higher courts. Eventually a small percentage of civil suits end up in the Supreme Court. Supreme Court rulings are considered "final" and often referred to as "Benchmark Cases." Read **ncd.gov/publications/2002/Sept172002** or a comprehensive list of the most important Supreme Court rulings under the ADA.

GROVE

Olmstead v. LC

One of the most important rulings was Olmstead v. L.C. It is arguably the most important civil rights decision for people with disabilities in our country's history. This 1999 United States Supreme Court decision was based on the ADA's "integration mandate" which requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." See the *Disability Rights* chapter in the Nut section for more information.

Protection and Advocacy

The Protection and Advocacy (P & A) Programs were created to protect the rights of people with disabilities. They were congressionally mandated, starting in 1973 (not as a result of the ADA), but P & A programs were expanded under the ADA. A comprehensive list of P & A programs can be found here: **ndrn.org/about/paacap-network**

Each state is mandated to have its own P & A program. To find the P & A program in your state, go here: **mindfreedom.org/protection-advocacy**

Justin Dart, considered by many to be one of the "fathers" of the ADA, took the position that involuntary treatment for individuals labeled with psychiatric disabilities should stop.

Unfortunately, the P & A programs never developed the teeth to fight the expansion of involuntary treatment. Some claimed this to be an issue of underfunding but the P & A programs tend to reflect the political realities of our times. Many activists argue that for several decades, the mental health system has been unduly influenced by special interest organizations and has very little interest in human rights.

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Protection and Advocacy for People Labeled with Mental Illness

Legal representation for people with disabilities is incredibly important. According to Psych Rights, most individuals considered to be psychiatrically disabled who are forcibly treated or institutionalized do not receive adequate legal representation in court hearings:

> "A 2007-2008 study of the performance of attorneys representing people facing commitment in San Diego County, California,16 found the average duration in contested cases was 22.3 minutes, the longest lasting 44 minutes and the shortest 7 minutes. Professor Michael Perlin, the foremost expert on United States Mental Disability Law has noted, "If there has been any constant in modern mental disability law in its thirty-five-year history, it is the near-universal reality that counsel assigned to represent individuals at involuntary civil commitment cases is likely to be ineffective."—View full report on Psych Rights website: mindfreedom.org/next-level

PAIMI

Protection and Advocacy for People with Mental Illness (PAIMI) is administered by the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Center for Mental Health Services (CMHS). PAIMI uses federal grant funds to:

1. Investigate incidents of abuse and neglect on behalf of individuals labeled with mental illness in a public or private facility rendering care or treatment

2. Pursue administrative, legal (individual and class action litigation), systemic and legislative activities, or other appropriate remedies to redress complaints of abuse, neglect, and civil rights violations

3. Ensure enforcement of the United States Constitution, Federal laws and regulations, and state statutes as related to this area

In the section "The Cures Bill" it should be clear to readers that the

GROVE

political climate in the US is moving dangerously away from the spirit of justice that led to the passage of the ADA.

Starting in 2016, some mental health advocates such as E. Fuller Torrey of the Treatment Advocacy Center (TAC) argued to defund PAIMI on the basis that it provided legal support for individuals wishing to fight treatment by force!

United Nations Weighs in on Disability Rights

The United Nations created an international treaty called the "Convention on the Rights of Persons with Disabilities" (CRPD).

CRPD was adopted on December 13, 2006, at the United Nations Headquarters in New York, and was opened for signature on March 30, 2007.

The UN convention has now been signed by 187 countries worldwide, and ratified (made legally binding) by 177. To find out if your country ratified this treaty, view: **mindfreedom.org/CRPD-ratified**

One of the countries that has NOT ratified CRPD is the United States. One reason may be that CRPD calls involuntary treatment a form of "torture," a position which is not consistent with the widespread acceptance and use of forced psychiatric interventions in the US.

According to a press release by Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) posted on the website of National Association for Rights, Protection, and Advocacy (NARPA):

> "The 2008 Special Rapporteur report names forced psychiatric interventions (such as psychosurgery, electroshock and

GROVE

administration of mind-altering drugs including neuroleptics) among practices that may constitute torture or ill treatment. Other medical practices that may constitute torture or ill treatment are restraint and seclusion, forced abortion or sterilization and involuntary commitment to psychiatric institutions. The medical context itself is one where 'serious violations and discrimination against persons with disabilities may be masked as 'good intentions' on the part of health care professionals.'" More: **mindfreedom.org/forced-treatment**

Items for Action

- View a slideshow by activist/leader David Oaks. Oaks taught a popular workshop entitled "Amplify" to teach psychiatric survivors how to work effectively with people with disabilitie: **mindfreedom.org/david-slideshow**

- Support disability activists in your community

- Mental Disability Advocacy Center (MDAC) uses litigation to achieve social change for people with disabilities: **mdac.info**

- National Disability Rights Network (NDRN) works to improve the lives of people with disabilities by guarding against abuse and advocating for basic rights: **ndrn.org**

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Coming Out of the Shadows: Learning to Tell Your Story

by Emily Cutler

One of the most important things you can do as an activist is to share your own story. Stories have infinite potential to humanize social issues and incite public consciousness. One reason that narrative communication is one of the most effective forms of communication is that it allows audience members to put themselves in the narrator's shoes, transporting themselves into their world and experiencing the events as they did.

In addition, you personally sharing your story with friends, family members, coworkers, colleagues, and others who know you can play an important role in raising awareness about psychiatric abuse and coercion within your community. Think about it: if you found out that your best friend, or respected colleague, or beloved family member, were highly affected by a specific health issue or social justice issue—let's say breast cancer—well, you'd start caring about breast cancer (or whatever the issue may be) pretty quickly, wouldn't you?

Two important recent movements that show the incredible impact of storytelling are the LGBTQ movement and the #MeToo movement. In the LGBTQ movement, lesbian, gay, bisexual, trans, and queer people help to advance social change by coming out and sharing their sexual orientation or gender identity. In the #MeToo movement, sexual assault survivors

heroically came forward with their stories, refusing to be silenced by a victim-blaming culture. In both cases, activists who spoke out (and continue to speak out) about their personal identity and story have helped to show how prevalent and important the issues are, and to reduce the shame surrounding these narratives.

Like the thousands of stories that comprise the #MeToo movement, your story can also be a powerful tool in challenging victim-blaming. Because of the pervasive stereotypes of people with psychiatric diagnoses as irrational, dangerous, and aggressive, many people have been led to believe that they deserve to have acts of violence committed against them such as psychiatric imprisonment and forced drugging. In other words, people with psychiatric diagnoses are often seen as perpetrators, not victims. Your story can be an impactful way of acknowledging the legitimate victimhood and oppression of people with psychiatric diagnoses as a marginalized group. The more stories that are told, the more people will realize that individuals with psychiatric diagnoses, like LGBTQ people and sexual assault survivors, are a group that has been wronged and deserves justice.

A final benefit of sharing your story is that it can be a very helpful way of connecting with others who have experienced similar abuses and injustices. Your story can validate others, letting them know that they are not alone in their feelings of anger, hopelessness, and trauma due to their experiences with the psychiatric system. In turn, receiving positive feedback and support for sharing your story can help you feel less alone as well. Finley Peter Dunne once said that the purpose of good journalism is to "afflict the comfortable and comfort the afflicted." A powerful story can accomplish the same.

You can share your story in a variety of ways. You might wish to start by telling your story to close friends or trusted family members. For a more public recounting of your story, you might wish to publish your story in a magazine or blog, write an op-ed for a newspaper, give testimony at a public hearing or town hall meeting, speak at an open mic, or film a short video. But you don't need to create an artistic masterpiece or eloquent speech to be able to get the word out about what happened to you—even a Facebook post or a tweet can reach many people (and besides, who's to say a Facebook post or a tweet can't be an artistic masterpiece?). You can also tell your story visually with a painting, photograph, or comic strip.

It might be most comfortable for you to try out a number of different methods and modalities for sharing your story, starting out with more informal venues and working up to more formal mediums like a published article. Activist and stand-up comic Jim Flannery suggests:

> "If you are looking to speak your mind or share your story, and you are scared, that is normal . . . it can be a very scary thing. One approach which I find really effective, is to ease into things slowly using different means of communication. Maybe start with an anonymous Twitter account posting your thoughts and ideas. Maybe start a private journal that only you can read. Then trying writing a blog that is public and affiliated with your name. Try commenting on other people's posts in places like Reddit or Tumblr. Go to events where people are speaking about mental health and then ask questions after their talks. Maybe attend a protest with speakers and people having discussions about these issues. Get involved in these more minor, safer ways to become more and more at ease with having these conversations. Then your comfort zone will slowly stretch and you'll be more capable of speaking out. For me, doing stand-up comedy allowed me to speak about these things . . . but it took several years of telling jokes before I was ever able to say something publicly in a 'serious' manner . . . it takes time and practice, like any other skill."

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Below are the elements of any good story. While these elements are most often discussed in the context of written memoir, they can be found in a story that is told through any medium, including visual and spoken stories. As you read about these elements, think about how they apply to your own story. It may be helpful to jot down some notes as you read.

Theme

If you are telling your story for advocacy or activism purposes, the theme is the most important element. The theme of a story is the underlying idea or message of the narrative. In fables, this is the "moral of the story." One helpful way to think about the theme of your story is to ask yourself, "What lesson or knowledge do I want people to learn after reading my story?" In other words, how do you want people to change as a result of reading your story?

Some possible themes you'd like to include in your story are the abusive nature of the mental health system, the impact of psychiatric coercion, societal prejudice and stereotypes of people with mental health diagnoses, and the effects of criminalization or homelessness. Your goal might be for the audience to:

- Understand the traumatic effects of involuntary commitment and/or forced drugging
- Gain awareness of sanism i.e. prejudice against those with psychiatric diagnoses
- Be motivated to take action against civil rights violations in the mental health system
- Feel angry about the systemic marginalization and abuse of those with psychiatric diagnoses

The theme and intended impact of your story should shape all of the rest of the elements. Once you have decided what you want to accomplish in telling your story, you can make decisions about what you want to include in your narrative based on what will or will not serve that purpose.

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Keep in mind that you may have different intentions for different tellings and venues of your story. For example, if you are writing your story in an op-ed for your local newspaper, your goal may be to inspire readers to take political action. If you are telling your story to a close friend or family member, your goal may be to help them understand the trauma you have been through. If you are telling your story to other psychiatric survivors, your goal may be to help them feel less alone.

"You own everything that happened to you. Tell your stories. If people wanted you to write warmly about them, they should have behaved better."

Anne Lamott
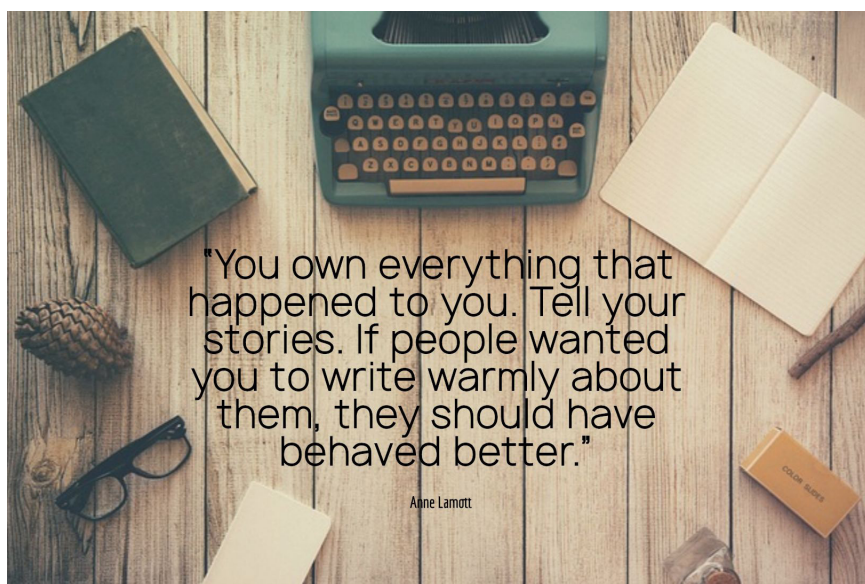
Characters

Another important element of every story is the characters. Before telling your story, you will need to decide who the central characters of the story are, and what role they play. One central character will, of course, be yourself. You will need to decide how you want to portray yourself in the story and help your audience get to know you, your thoughts, and your feelings. The more personal and vulnerable you are willing to be, the more audience members will be able to relate to and connect with you as a character. Other central characters may include your family members, friends, and mental health professionals.

GROVE

Remember that the way you choose to describe your characters and help the audience get to know them should serve the purpose and theme of the story. For example, if the purpose of the story is to expose how dehumanizing the mental health system is, it may be helpful to include vivid descriptions as well as specific actions and dialogue of any mental health professionals that were particularly condescending or abusive. If one of your goals is to show how beneficial peer support is, it might be helpful to provide details, actions, and dialogue of a particular peer provider that was supportive in your recovery.

It is impossible to include every person who has had an impact on your life (or on your experience of the mental health system) in your story, so you will need to decide who the most important characters are. You may also wish to combine multiple characters into one character.

Setting

You will also need to think about where your story takes place, and how you want to describe that place. A story can, of course, take place in multiple settings. For example, perhaps you experienced childhood trauma that caused mental health struggles and led to involvement in the psychiatric system in adulthood. If this is the case, the settings in your story might include your childhood home as well as psychiatric hospitals and/or outpatient clinics.

An important question to ask yourself is, "How do I want to describe these settings?" Often, when discussing the setting, it is helpful to include specific sensory details—what did the place look like? Sound like? Smell like? Were there any tastes you can remember? How was the temperature—was it burning up or stone cold? These details, too, should serve the theme of your story; for example, if the purpose of the story is to raise awareness about the abuses in the mental health system, you may want to describe the prison-like or sterile conditions of the psychiatric hospital.

Plot

Perhaps the most daunting part of telling your story is figuring out how to structure it, and what events to include or exclude. The diagram below can help you begin to think through decisions about the plot of your story—the answer to the question, "So what actually happened to you?" The diagram is a standard plot diagram used to illustrate the narrative structure of many stories, and includes the following elements: exposition, rising action, climax, falling action, and resolution. Below is a brief description of each:

- **Exposition:** The setup. This is the background information that the reader needs to know in order to understand your story.

- **Rising Action:** A series of relevant events that create suspense and tension, and lead up to the climax. This usually includes conflicts between characters as well as internal conflict in the narrator.

- **Climax:** The highest or most intense point in your story. This is usually a major turning point in the story.

- **Falling Action:** A sequence of events that begin to wrap up the story.

- **Resolution:** The ending of the story. In an advocacy story, this often includes some sort of reflection or call to action.

Tension peaks
Climax

Narrative and dramatic tension build

Rising action

Narrative and dramatic tension ease

Falling action

NOW NOVEL

Exposition
We meet characters, the primary situation

Resolution
The story comes to a close
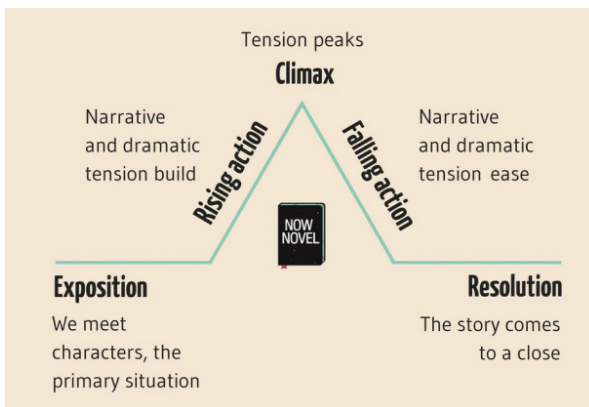
Before you tell your story, it may be helpful to outline the above parts of your story. Because it is impossible to include every event or moment that forms a part of your experience, you will need to make decisions about the most important events to include. The above diagram is a useful tool in deciding what to leave in and leave out.

GROVE

To illustrate the points of the plot diagram, below is a powerful story from a key activist in the early psychiatric survivors movement, Judi Chamberlin:

CONFESSIONS OF A NONCOMPLIANT PATIENT

I tried hard to be a good patient.
I saw what happened to bad patients: they were the ones in the seclusion rooms,
the ones who got sent to the worst wards,
the ones who had been in the hospital for years,
or who had come back again and again.
I was determined not to be like them.
So I gritted my teeth and told the staff what they wanted to hear.
I told them I appreciated their help.
I told them I was glad to be in the safe environment of the hospital.
I said that I knew I was sick, and that I wanted to get better.
In short, I lied. I didn't cry and scream and tell them that I hated them and their hospital and their drugs and their diagnoses, even though that was what I was really feeling. I'd learned where that kind of thing got me—that's how I ended up in the state hospital in the first place. I'd been a bad patient, and this was where it had gotten me. My diagnosis was chronic schizophrenia, my prognosis was that I'd spend my life going in and out of hospitals.

--Judi Chamberlin (1998, p. 49)

WWW.LAURENTENNEY.US

"Although the story is short, it does include all of the plot points. We learn very early on—within the first two lines—that Chamberlin is a mental patient (exposition). In the rising action, Chamberlin describes what happens to noncompliant patients, leading to her decision to not be like them in order to avoid punishment (the climax). In the falling action, Chamberlin describes more about the actions she takes after making this decision. Her final line is a reflection on what she has learned about what happens to 'good' and 'bad' patients (resolution)."

Showing vs. Telling

An important guideline to try to follow when telling your story is,

"Show, don't tell." In other words, rather than merely summarizing or paraphrasing the events of your story, allow your reader to experience your story with you through action, dialogue, and sensory details, as well as your own thoughts and feelings. Below is an example to illustrate the difference between showing and telling. The "showing" paragraph is from a piece called ***"A Story of Forced Hospitalization from a Legal Perspective"*** *by Nikki Jimenez.* mindfreedom.org/showing-telling

> **Telling:** "My psychiatrist was very condescending. On the second day of my hospitalization, he insulted my appearance, which I found to be incredibly rude and dehumanizing."

> **Showing:** "I met my psychiatrist on the second day. In his 70's and well established, he would waste no time making clear the balance of power during my stay. After discussing my symptoms, the conversation turned to my personal life and how I was planning on starting law school that year. He said that I should use this hospitalization as an opportunity to better myself both physically and mentally. 'You have such a pretty face,' he said, 'and would look great if you just lost 15-20 pounds.' Besides, he explained, studies showed that overweight women were discriminated against in hiring interviews. If I just 'lost a little weight and looked cute in a skirt and some make-up,' I'd have an easier time getting legal jobs.

> Shocked, indignant, and principled above all else, I looked him dead in the eye. 'I plan on getting hired based on being the most qualified applicant for the job and not on the basis of having a body they'd like to [expletive deleted].'"

As you can see, the second description is much more vivid and compelling than the first, and better allows the audience to transport themselves to the world of the story. It also allows the audience to better get to know the characters of the story—both the narrator and her psychiatrist—and advances the theme of the story, the violation of patients' rights to be treated with dignity and respect when seeking treatment.

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Resources

Now that you know the basics of telling your story, what are you waiting for? Below is a list of resources that may be useful to you in the process of learning to share your story.

Mad in America: a critical psychiatry web magazine that publishes news, research, and blogs critiquing the drug-based paradigm of mental health care. They also publish personal stories written by people who have experienced psychiatric harm as well as visual art, poetry, and music by people with lived experience. For more information, visit: madinamerica.com

The Mighty: a disability and mental health blog that publishes pieces about people's experience of distress and disability. While many of the articles report positive experiences with the mental health system, critical pieces and negative accounts have been published there as well: themighty.com

Theatre of the Oppressed: can be a very important medium for sharing your story and has been used as a tool for social change throughout history (a prominent example is the use of theater to raise awareness about the AIDS crisis). To learn more, you may wish to read Theatre of the Oppressed by Augusto Boal, which describes methods for creating social change through theater: mindfreedom.org/theatre-oppressed

Portland Story Theater: a nonprofit that helps bring the lived experience of diverse individuals and groups of people on stage. Previous projects have included staging the stories of cancer survivors, veterans, and other narratives of trauma: pdxstorytheater.org

Poetry for Personal Power: a nonprofit that empowers people with lived experience to tell their stories via the medium of spoken word: poetryforpersonalpower.com. View performances by founder and CEO Corinna West: youtube.com/user/CorinnaWest816

Mad Mad Memez: raises awareness about the psychiatric survivors movement, Mad Pride, and psychiatric coercion through memes (digital images that often include text): facebook.com/madmadmemez

Items for Action

·   Submit your personal story, visual artwork, poetry, or music to Mad in America, a web magazine that seeks to bring about change in the mental health system. For instructions and to view other's personal stories and artwork, visit: madinamerica.com

·   Submit a short piece about your experiences of emotional distress or the mental health system to The Mighty, a popular mental health blog. Learn more at: themighty.com

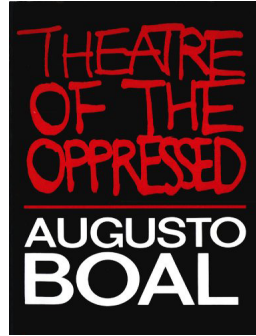·   Visit poetryforpersonalpower.com to learn about Poetry for Personal Power, a nonprofit that empowers people with lived experience to tell their stories via the medium of spoken word

·   Read **Theatre of the Oppressed** by Augusto Boal to explore theater as a medium for sharing your story and advocating for social change

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Mad Pride

by Emily Cutler

While there are many critics and survivors of psychiatry efforts on championing alternative treatments for people diagnosed with mental illness, Mad Pride goes a step further by questioning the need for any kind of treatment or recovery at all.

The Mad Pride movement is a paradigm that finds value in and even celebrates the traits, characteristics, states, thoughts, feelings, and experiences that are usually categorized as mental illness or madness by psychiatry, the **DSM**, and society.

Instead of framing distress and difference as a problem that needs to be eliminated through medical or behavioral treatments, the Mad Pride movement argues that these experiences exist along the spectrum of human diversity.

The Mad Pride movement parallels many other social justice movements,

primarily the LGBTQ Pride movement and the Disability Pride movement. Although being lesbian, gay, bisexual, and transgender have a history of being pathologized as disorders in the **DSM**, the LGBTQ Pride movement argues that these sexualities and gender identities are valid forms of diversity that should be accepted in society. Similarly, the Disability Pride movement argues that there is nothing inherently wrong with being disabled; rather than trying to "fix" an individual's disability, we should focus on providing accommodations and acceptance to disabled people. The Mad Pride movement applies these arguments to people with psychiatric diagnoses.

Like the LGBTQ's reclamation of the word "queer," the Mad Pride movement reclaims the word "mad," arguing that madness can be an identity and a culture, not a negative, scary disease that the word usually represents. For this reason, Mad Pride activists often prefer identity-first language rather than person-first language, i.e. "Mad person" rather than "person with madness" or "person with mental illness." Claiming the adjective as a descriptor of one's identity helps get across the message that it is a part of who one is, not a separate entity that can be eliminated. Many Mad Pride activists also capitalize the word "Mad" (as I have in this chapter) to represent its cultural and identity-based meaning.

Mad Pride does not deny the reality that the states, traits, and characteristics usually categorized as mental illness are often associated with deep emotional and mental suffering. Rather, the Mad Pride movement questions whether experiences of deep emotional and mental suffering indicate a pathology or a symptom of an individual issue that

GROVE

needs to be treated. Many Mad Pride activists work to highlight the social, systemic, familial, and contextual causes of distress, positing that madness is a natural response to being made to feel powerless, isolated, devalued, rejected, or marginalized. Their efforts often focus on systemic and cultural change to help bring about spaces, communities, and families where individuals feel valued, included, and loved for who they are. In this regard, madness can serve as an important tool in enabling activists to be righteously angry, sad, panicked, traumatized, fearful, and/or outraged by systemic injustice, and can fuel their determination to do something different.

That is not to say that the Mad Pride movement opposes taking measures to alleviate individual suffering! Just as some people like to drink coffee to stay more alert or take ibuprofen to relieve physical pain, sometimes substances can be tremendously helpful in helping ease distress. And, just as all kinds of people have sought out helpful counsel and advice from priests, rabbis, secular humanist chaplains, psychics, and trusted advisors for centuries, all kinds of people (including Mad people) can benefit from seeking the expertise of a professional psychologist, therapist, or peer specialist. What Mad Pride contests is the idea that any of the above corresponds with a need to be treated or fixed.

Central to the Mad Pride movement is the notion of Mad autonomy—that those with psychiatric diagnoses should have the right to make their own decisions about how to conceptualize their own identities, emotions, and health, as well as what (if any) supports or treatments to seek. Another way to describe the idea behind Mad Pride is that people with psychiatric diagnoses should have the right to react to their emotional distress or mental differences in whatever way they choose or that feels most comfortable to them. For some, this might involve lying in bed all day and watching television; for others, this might involve dialoguing with and co-existing with voices or visions; still for others, this could be using (prescribed or unprescribed) drugs or self-injury to cope.

Another concept that is closely tied to the Mad Pride paradigm is that of cognitive liberty, a philosophy that encompasses the rights of individuals to (1) alter their consciousness in whatever way they choose and (2) not have their consciousness altered against their will. Coined by Timothy

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Leary, a psychedelics researcher, cognitive liberty advocates originally focused on the rights of people to take psychedelics and other mind-altering drugs; it is now a term that is embraced widely by Mad Pride activists.

Below are some examples of statements that are representative of the range of views and perspectives of those who conceptualize their identities within the Mad Pride paradigm:

1. I really love hearing voices. It helps me feel less alone. But what I hate is how everyone responds to my voice hearing, as if I am crazy or completely irrational. It is sanism, not hearing voices, that causes me so much suffering.

2. I feel that experiencing extreme distress in response to social injustice motivates me to create a more just, fair society.

3. Having experienced the depths of madness has helped me become more empathetic toward others who are in distress and going through hardships.

GROVE

4. I hate being depressed and anxious all the time, but I don't think it means there's anything wrong with me. I think it's a natural reaction to having to live in a capitalist society that solely values me based on what I can produce, not based on who I am.

5. I don't really like having my mental differences, but I also don't think they can be cured or eliminated, at least not without some very time-consuming, expensive, and distressing treatments. Like it or not, they are part of who I am and I'd at least like them to be accepted within society.

Of course, these statements can all be true for one single person. They are all true for me for different aspects of my madness. The important takeaway here is that Mad Pride is not a set of rules for how you should or shouldn't feel about your psychiatric diagnosis, mental difference, or personality. The goal of Mad Pride is to include a broad range of perspectives and individual truths while advocating full autonomy and choice.

The following are a few more in-depth examples of what Mad Pride can look like for different characteristics or experiences.

Multiplicity

Multiple systems (systems for short) are comprised of two or more people who share one body. The notion of multiple people sharing one body is often pathologized by psychiatry and ridiculed by society. Even among professionals and family members who are critical of psychiatry and the mental health system, there may be efforts to cure or eliminate multiplicity by "integrating" the members of the multiple system into one person. Many multiple systems are working to change this by taking a Mad Pride stance on multiplicity.

Missy and Skylar Freels, two such activists, say, "We're not dysfunctional or bad just because there are two of us in here. What's more important than being a socially acceptable single person is that we know how to get along and manage our trauma and our life together. Knowing this, we now strive to advocate for other systems and reach out to those that may not understand systems, to show that existing as we do is okay and that

we can learn to navigate the world by cooperating. We don't need the psychiatric system or its labels to allow us to exist, or to try to fix us. We just need to be accepted as we are."

Spiritual Emergence

The spiritual emergence community is a space for people who have gone through deep, intense levels of emotional distress and crisis, and who feel that their experiences have made them more spiritually in tune and in touch with the world. Individuals in the spiritual emergence community often conceptualize their mental differences as increased sensitivity to phenomena that often go unnoticed. While the experience of crisis is often deeply distressing and life-disrupting (sometimes referred to as "spiritual emergency"), many people in this community feel proud to have gone through it and consider their increased spirituality an important part of their identity. A major initiative carried out by people who have gone through a spiritual emergence is called the #EmergingProud Campaign, which works to reframe mental distress as a transformation process.

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Chris Cole, an author and coach who has experienced spiritual emergence, eloquently speaks to the spiritual value of his experience of madness: "I spent years vacillating between the legitimacy of psychopathology and spiritual emergency, but eventually I realized that the dichotomy between madness and insight was a false one. The extent to which anyone is permitted to step out of consensus reality has always been constrained by social mandates. These social forces go unnoticed, almost entirely unconscious, until a person has an awakening or epiphany to some sense of unconditioned reality. Madness is one such method of glimpsing the unconditioned state, a psychic feature built into the human experience.

Though the mad experience can be horrific and painful, there is nonetheless an opportunity to cross impasses that were previously invisible to us. I see bipolar bodies as more susceptible to madness, and the trials of such experiences are largely exacerbated and perpetuated by a society that suppresses interconnection, creativity, and love."

Your Own Mad Pride

In thinking about Mad Pride for yourself, and considering it as a way to think about your own identity or experiences of distress/extreme states/difference, the following questions may be helpful:

1. What do you like/enjoy/find positive or valuable about your own experience of emotional distress/mental difference? Has the experience . . .

    ·   Made you more empathetic to others who are struggling?

    ·   Motivated you to engage in activism?

    ·   Helped you to better understand social injustice?

    ·   Enabled you to become more spiritual?

2. What would a society/community that is accepting of your particular mental differences look like? How would it feel to be surrounded by people who not only accept but value your differences?

3. What types of sanism have you experienced due to your madness/mental differences? Have you experienced . . .

    ·   Stereotyping?

    ·   Bullying?

    ·   Workplace or hiring discrimination?

    ·   Social rejection?

    ·   Involuntary commitment?

    ·   Forced drugging?

    ·   Criminal justice system involvement?

4. What does the word "mad" mean to you? What about other slurs used against people with psychiatric diagnoses—crazy, psycho, loony, nuts, etc.? How would it feel to reclaim these words as something positive?

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Effective Community Organizing Tactics for Psychiatric Survivors & Allies

by David Oaks

Lunatic. Crazy. Nuts. Cuckoo.

Our society can diminish a person in many ways by gender, ethnicity, income, age, ability, etc. But one of the most powerful ways that a person can be dismissed, ignored, demonized, and made invisible is to label them as "mad." Some of us in the psychiatric survivors social change movement have even redefined the word M.A.D as an acronym: Marginalized And Disempowered.

Psycho. Bonkers. Bananas. Maniac.

These are such negative labels. How can we ever have any pride, dignity, or self-respect when we are considered mad?

Whacko. Schizo. Deranged. Insane.

But for centuries, though it is little-known, out of the spotlight, those of us who have personally experienced the mental health system have organized groups, spoken out to politicians and the media, and created social change that has improved the lives of people whom society considers "mad."

For instance, back in 1620 in London, England, where the horrible Bethlem Hospital (pictured on the next page) gave us the word "Bedlam," inmates united and delivered a "Petition of the Poor Distracted People in the House of Bedlam (concerned with conditions for inmates)" to UK's Parliament.

Engraving by Robert White c. 1676 - Edward Geoffrey O'Donoghue, The Story of Bethlem Hospital from its Foundation in 1247 (London, 1914), Public Domain, https:commons.wikimedia.org/w/index.php?curid=22451201

On July 7, 1845, also in the UK, the Alleged Lunatics' Friend Society formed. During the next twenty years, the Society lobbied Parliament and campaigned through the media and public meetings for a more compassionate mental health system. They took up the cases of more than seventy survivors.

But it was in the late 1960s and early 1970s that the modern era of the psychiatric survivors movement began. There was enormous social change ferment because of civil rights leaders, peace activism, the women's movement, environmental protests, and many other movements for equality and justice. This immense turmoil provided the sunlight, soil, and rain for the inspiration and hope that made speaking out seem natural for psychiatric survivors. So of course, the psychiatric survivors movement did not spring out of a vacuum. Supported by concerned attorneys, dissident mental health professionals, and some caring family members, this diverse network has since grown internationally and has an increasing influence today. How have psychiatric survivors and mental health consumers been able to win victories in the face of such intense discrimination?

Building Peace in a Violent Mental Health System

One of the main models for the modern era of psychiatric survivor activism is the US Civil Rights Movement. For example, Martin Luther

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King Jr. often framed his work as a positive challenge to what is widely considered conventional or "normal." In over ten of his speeches and essays, for about a decade, he said in different ways, "There are some things in our nation and in our world to which I'm proud to be maladjusted." It is highly recommended that everyone who cares about change in the mental health system become familiar with Martin Luther King's use of this term "maladjusted." He believed that "human salvation lies in the hands of the creatively maladjusted." In fact, he even repeatedly said the world was in dire need of a new organization, the "International Association for the Advancement of Creative Maladjustment" (IAACM).

MLK often pointed out that his social justice work was beyond

transforming racism. He frequently talked about his goal of reaching a "beloved community." The psychiatric survivors movement is also beyond challenging the mental health industry. Ultimately, this work is about affirming the human spirit itself, a spirit that never ever gives up.

Confronting the mental health industry abuses can feel overwhelming. In 2018 the nonprofit group Mad in America surveyed 500 people who have used the mental health system. More than half of respondents reported that their psychiatric ward experience was "traumatic." While this was an informal poll, it is revealing that only 17 percent were "satisfied with

the quality of the psychiatric treatment" they received. Abuses such as solitary confinement, restraints, forced drugging, etc. continue globally. In the MIA survey, more than one-third reported physical abuse such as involuntary treatment. See more details about the survey: **mindfreedom. org/survey-abuse-mental-hospital**

The MindFreedom International office frequently hears about these human rights complaints. Families with a loved one going through crisis often have great difficulty finding and accessing empowering, humane options for mental and emotional care. Those who are prescribed psychiatric drugs often report they do not get full and complete information about hazards involved with lifelong psychiatric drug use or problems associated with psychiatric drug withdrawal, or data about effective, nondrug alternatives.

It is not the purpose of this chapter to list all the abuses and violations in the mental health system. But we can learn some of the lessons from those who have somehow challenged this powerful industry and created positive change.

As the civil rights movement taught us, the ends and the means are connected. In order to create a peaceful mental health system, we need groups that use peaceful methods and teach peaceful values. Mutual, respectful, supportive peer support is not just a goal of our movement. Positive mutual peer support is one of the main ways we have the unstoppable power to seek change in the face of a deadly and disdainful mental health industry.

The heart of true social justice organizing is to connect with other movements. That is why we need more than reform, we need a positive revolution throughout the globe. Psychiatric survivors are not in this struggle alone. Here are just a few of the ways that our movement connects with others:

· **Prison justice:** Whenever any of us has their liberty taken away, for any reason, we are "prisoners." In the 1970s, this was one of the main struggles that our movement saw as closest to our own. Even today, people in the prison system are often coercively drugged

GROVE

or in some cases denied the type of treatment they need, making many modern prisoners psychiatric survivors. MindFreedom International now has a Prisoner Project to learn more about these violations and empowering alternatives.

Anonymous gay psychiatrist (John E. Fryer) in a modified Nixon mask speaking out for human rights in a 1972 news conference to confront the APA. Kay Tobin Lahusen - New York Public Library Digital Gallery.

· **LGBTQ+ Movement:** One of the major historic steps was when activists successfully pressured the American Psychiatric Association (APA) to change their definition of the "disorder" of homosexuality. This action only resulted in a partial victory because although the APA substantially modified its definition, it did not totally remove gender-preference disorder. But this historic win helped illustrate the close connections between these two movements. An audio program about this campaign can be found here: **mindfreedom.org/homosexuality-dsm**

· **Women's Rights:** Twice as many women as men, on average, receive some of the most intrusive psychiatric procedures, such as electroshock: **mindfreedom.org/electroconvulsive-therapy-women**

· **Fighting Racism:** The unscientific biological model that currently dominates the mental health system can be inherently racist. Several reports show that people of color are far more represented among those who experience involuntary psychiatric drugging and at higher dosages. For example, New York State has had a program for court-ordered outpatient psychiatric drugs that proponents called "Kendra's Law." A study of the results showed that Black people were nearly five times as likely as White people to be subjected to this law. Download study: **mindfreedom.org/kendras-law-racism**

To be alive is to experience some amount of trauma. Of course, all people throughout their lives go through diverse mental or emotional challenges, to a greater or lesser extent. Today, we know through countless scientific studies that the future of civilization, and perhaps the

GROVE

future of living species themselves, relies on profound social change. The current ecological crisis shows that all humanity faces the challenge of addressing reality in a way that can be sustaining.

Within the conventional mental health system, one frequently hears a debate about how many people are experiencing serious and persistent mental disorders. Is it 15 percent? Is it 25 percent? A valuable but challenging lesson from the psychiatric survivors movement may be that 100 percent of everyone, continuously, experiences overwhelming and potentially life-threatening mental and emotional challenges. Perhaps none of us has a grip on "reality." That is one of the main reasons we need a peaceful community for everyone. We need each other, just to exist, and to strive for justice. This is what MLK called the "beloved community."

Unity Through Diversity: The Many Words for Liberation

MENTAL DISORDERS ARE NOT ADJECTIVES

MY MOM YELLED AT ME YESTERDAY SHE'S SO BI-POLAR!

YOU ALMOST GAVE ME A PANIC ATTACK!

YOU LOOK SO ANOREXIC!

QUIT BEING PSYCHO!

MY O.C.D. IS COMING OUT AGAIN!

OH, YEAH. YESTERDAY I WAS FEELING REALLY DEPRESSED

I SWEAR I'M LIKE RETARDED

STAYED UP UNTIL 1 a.m. MY INSOMNIA IS SO BAD!
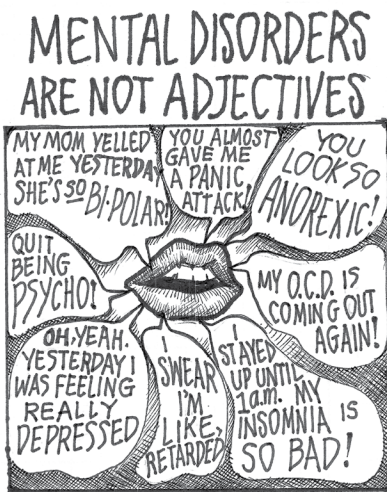
One of the most common activities in the psychiatric survivors movement is discussing what language to use for ourselves and our experiences. There is no perfect language to describe mental and emotional challenges. There is enormous diversity among us all. Some individuals personally identify with a psychiatric diagnosis, for example. Others totally reject all psychiatric diagnoses for themselves. How can we unite?

If you have personally experienced the mental health system, do you identify yourself as a "psychiatric survivor?" A "mental health consumer?" An "ex-inmate?" An "ex-patient?" Or a person with a "lived experience?"

Many in our movement have chosen to honor this diversity by using a number of letters to describe ourselves. The most common configuration is C/S/X, which stands for Consumer, Survivor, eX-patient.

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Suppose I Call Myself "Mentally Ill"?

What about the common phrase "mentally ill"? If you want to use that term about yourself that is one thing. But when anyone uses the phrase "mentally ill" about others without their permission, especially about activist psychiatric survivors, a big problem can arise. That phrase can carry a lot of "medical model" baggage, similar to words such as "symptom," "patient," and "chemical imbalance." The implication is that since an "illness" is the problem then a doctor ought to be part of the solution. "Mental illness" also says since the problem is like a physical illness, then perhaps the solution ought to be physical too, such as a chemical or drug or electricity.

At the end of this chapter, we have an "Items for Action" section, including links to original historic documents in our movement, such as a list of mental health jargon translated into plain English.

There is no concrete scientific evidence about what causes typical mental health challenges. The issue is about choice. What unifies our diversity is the goal of human rights. If you as an individual choose to accept mainstream mental health diagnoses and treatments, that is your personal, private decision. But if you use conventional mental health language for others, without their expressed approval, they may feel unfairly judged and diminished.

At this time, the "medical model" is dominant, but not proven. The medical model has become the bully in the room. Language that encourages that domination by giving legitimacy to an unproven model isn't helpful to the extremely deep change required in the mental health system. We need a nonviolent revolution of choice, empowerment, and self-determination. This rebellion must include the rejection of clinical language imposed on others in an oppressive way.

In other words, our social change movement is not in a fight with individual belief in a medical model. We are actually opposing the "bully model" in mental health. Where this diverse movement converges is supporting the framework of human rights.

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What's in a Word?
Do We Face Stigma or Discrimination?
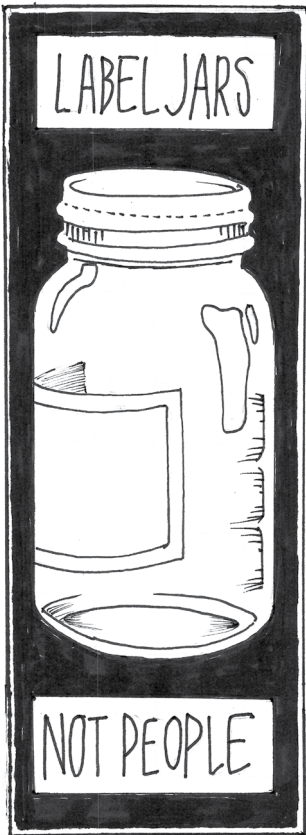
For similar reasons, activists in our social change movement prefer to talk about "discrimination" rather than "stigma" following a psychiatric diagnosis. Discrimination can be collectively challenged and changed, such as through legislation. Stigma is created socially and internally. The chapter entitled "Medical Model" in this handbook presented data that the conventional medical model for "mental illness" may actually increase stigma.

The word stigma originates from the word "branded," and has a negative connotation that implies that the identity of a psychiatrically labeled person is always unfavorable, which is not the case. Mad Pride defeats stigma!

Some activists have sought to reclaim the words society has thrown our way. You personally may not choose to use words like "mad," "lunatic," "crazy," or "bonkers" to describe yourself, ever. And we probably should not use those provocative terms in certain contexts, such as presenting our rights in front of the United Nations. But now and again, in reference to ourselves, some of us like to have some fun and be outrageous, such as at Mad Pride events, where it is okay to be creative and recycle language that has been used against us. This is us laughing with us, and with all of society, to further our goals. That's different than someone exploiting us for their own private goals.

In the right context, let's recapture some of the words used about us. We do, after all, get a lot of the fun animals such as squirrely, crazy like a fox, bats in the belfry, and loon.

Community Organizing Cycle Builds People Power

What is the role of national or international leadership in prioritizing and strategizing? How are we to unite hundreds of smaller groups and their priorities in their local communities?

Community organizing comes from the ground up. The heart of activism can be found in the small group of equal, mutually supportive individuals. This is the "horizontal model" of social change. Larger regional, national, or global leadership is based on human rights goals but bridges local activism.

Community organizing was pioneered by activist Saul Alinsky, and helps provide a framework for building people power. The cycle is quite simple: Your group selects an issue that is not too difficult or too easy. There are many criteria about choosing an issue. For example, a good issue is based on your group's strengths and the weaknesses of an opponent. A good campaign has many ways to involve your members. For this and other community organizing tips, we highly recommend the manual from Midwest Academy, listed in the "Items for Action" at the end.

After your group picks the campaign, members participate in actions to flex their people power. Crucially, when your group wins, there can be a variety of ways that this builds the group's people power. Like a recycling symbol, your group keeps building power with each win.

Unifying Through Human Rights: The Three "F"s of Involuntary Mental Health

Our movement includes a wide diversity of people and views. Some totally reject the mental health system. Others utilize aspects of this system. How can we work together? Our unity is about human rights, and so we stand united against psychiatric coercion of any kind.

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Mental health human rights violations are complex and numerous. There is no perfect, easy way to sum up this field, but here is a simple way to view the three types of coercion in the mental health industry:

1. **FRAUD:** Misinformation by a licensed mental health professional about benefits or risks of a treatment. For example: all known "informed consent" releases obtained by the MindFreedom office about electroshock falsely reassure subjects about the risk of memory loss.

2. **FEAR:** The mental health system does not provide a full range of healthy, proven, and empowering options for people experiencing mental or emotional problems. The message for mental health consumers, from the media and from many mental health professionals, is that rejecting conventional psychiatric treatment will likely lead to living in the streets or committing a violent act. Many of us are frightened into obeying our doctors because we want to avoid homelessness and prison. But if we truly had a wide variety of effective alternatives available, many of us would choose them.

3. **FORCE:** Court orders or outright physical coercion can be used to give a mental health procedure against the expressed wishes of the subject. Almost all US States now have laws that allow judges to court-order involuntary outpatient psychiatric treatment. This means that Americans can be required to take psychiatric drugs, even while living at home and out in the community. And as psychiatric survivors report, inside of many mental health facilities, a subject can be held down and forcibly injected with a psychiatric drug. Based on firsthand reports from many MindFreedom members, restraints and solitary confinement are often routinely used in such institutions.

Within this broad framework of human rights concerns, there are countless possible issues. We can learn from past victories about tactics and strategies that may support our efforts. Let's look at a few of the campaigns for human rights in mental health that have been successful.

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USA Quietly Limits Involuntary Psychosurgery

It is well-known that during the 1960s there were many urban riots. What is not well-known is that psychosurgery, such as lobotomy, was encouraged as a possible solution. For example, three doctors at the Harvard Medical School campaigned for the potential use of psychosurgery for social control. Following a major riot in Detroit in 1967, professors of surgery, Vernon Mark, William Sweet, and Frank Ervin, wrote a letter to the American Medical Association, blaming brain disabilities in some people as a potential cause of urban riots.
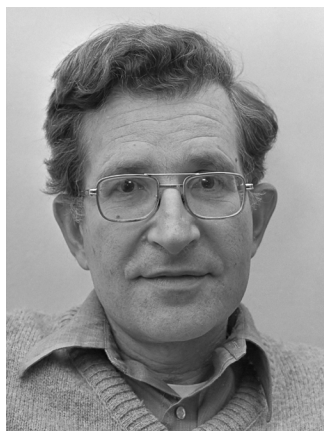
Noam Chomsky, December 8, 1977 by Hans Peters / Anefo - Nationaal Archief, CC BY-SA 3.0, https:commons.wikimedia.org/w/index.php?curid=39862498

The outrageous theory that types of lobotomy may help prevent urban riots led to a powerful reaction. For years, leaders in many areas of society, such as politics, academia, and medicine, spoke out and signed public letters denouncing the push for psychosurgery. The firestorm of controversy connected the grassroots with well-known activists. In the 1970s, the author and professor Noam Chomsky, internationally famous for his strong, progressive opinions, weighed in with his articulate views. Quietly, this united effort by networked progressives won.

In 1977, the National Committee for the Protection of Human Subjects of Biomedical and Behavioral Research recommended prohibiting involuntary psychosurgery. In the USA, all psychosurgery would require the permission of the subject. Because of the ethical issues involved, all psychosurgery of prisoners was banned.

True, this is only a partial victory against psychosurgery, which continues to this day in the US and several other countries. But this was a "win" against a certain type of involuntary psychiatric procedure. Unfortunately, by caving in, this Commission took the controversy out of the headlines, and today few know about this campaign. But we should remember this approach for future campaigns.

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MindFreedom Hunger Strike Exposes Lies

In 2003, a core group of MindFreedom activists gathered from around the US in a donated space in the Los Angeles area to hold a "Fast for Freedom." Together with supportive hunger strikers in other parts of the US, they won international attention. The hunger

Hunger strike activists, August 16, 2003.

strikers enlisted the support of dissident psychiatrists, psychologists, authors, and other thought-leaders to create a scientific panel. In a series of back-and-forth letters between the panel and the American Psychiatric Association, the APA was made to admit that they had no proof of chemical imbalances as a cause of major mental disorders. For more about the hunger strike: **mindfreedom.org/mfi-hunger-strike**

After several weeks of fasting, the action was covered in several major media sources, including *The Washington Post,* NPR, BBC, and others.

Ray Sandford was receiving weekly court-ordered, outpatient involuntary electroshocks, even though he was living peacefully in his group home out in the community.

Ray's Involuntary Outpatient Electroshock Stopped

MindFreedom held an international campaign in 2009 that ended the court-ordered outpatient electroshock of Ray Sandford of Minnesota. A judge had ruled that Ray, then fifty-five years old, receive electroshock (also known as electroconvulsive therapy) against his clearly expressed wishes. Each Wednesday morning a van pulled in front of Ray's group home and he was required to go to a nearby hospital to have shock. After dozens of coerced shocks, somehow Ray had the smarts to ask at his local library for the phone number of a human rights group. The reference librarian gave him the number to MindFreedom.

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MFI activated hundreds and then thousands of supporters using the media and even sending a delegation to lead protests in Ray's hometown in Minnesota. MFI activists used a wide variety of effective tactics, including issuing alerts, distributing thousands of leaflets, finding a new psychologist and attorney for Ray, photographing and filming Ray and his mother for the Internet, etc.

Finally, on a day that Ray was scheduled for more coerced shock, MFI activists repeatedly contacted the hospital and referred to recent national articles and his lawyer's arguments, and the shock was canceled. Ray was only a few dozen feet from the shock table when that shock was stopped. As of this publication, as far as we know, Ray is still free from shock.

Forming a Local Grassroots Coalition

Can groups that want major, deep change in the mental health system work well with organizations that are more moderate? Yes— as long as core principles are always followed. For example, in 2007, the local MindFreedom affiliate in Eugene, Oregon, worked with an independent living center to form an informal coalition with more than a dozen other nonprofits. This alliance united for a goal that brought them all together, taking action and supporting the empowerment of local mental health consumers and psychiatric survivors.

Opal Whiteley (December 11, 1897—February 16, 1992), American nature writer and diarist

Even though the beliefs of people in each group varied a great deal, this Opal Network, as it was called, successfully held dozens of popular events, such as film showings and panels of speakers.

The name "Opal Network" was chosen to honor the life of one of the most famous authors to emerge from that region: Opal Whiteley (1897-1992) was a lover of nature and an extremely creative writer. Tragically, she ended up in a London psychiatric institution for the last few decades of her life.

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Some of the elements that helped the Opal Network be successful were:

· Only a few representatives from groups were active in planning, but they began by agreeing on guidelines for positive, civil communication.

· Each event had a very basic purpose that we all agreed upon: supporting the voices of mental health consumers and psychiatric survivors. Of course, at no time were any of the groups expected to take a position in violation of their principles.

· Opal Network was always held in a very public, accessible location such as the library. None of the events were held inside mental health facilities.

Potential Future Tactics of Psychiatric Survivors

It would be impossible to predict what tactics you might choose in the future, but we can give a few examples of possible effective directions.

For example, federal funding of the occasional use of involuntary electroshock continues to this day. If taxpayers knew that some of their income went to forcing this procedure, there would probably be major outrage.

US Feds Fund Involuntary Outpatient Drugging

One of the largest US government agencies to address mental health is now supporting programs for coerced mental health procedures out in the community. In 2016, Substance Abuse and Mental Health Services Administration (SAMHSA) began funding seventeen programs with more than $50 million for court-ordered involuntary mental health procedures of outpatients. This is very often psychiatric drugs, and effective nondrug alternatives could be offered but are usually not.

When the US taxpayer finds out that his or her money is paying for the coerced application of controversial mind drugs that can cause physical damage, brain injury, and death, there ought to be widespread outrage. A challenge is to prove to citizens that this unethical approach is being

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used. We have to show that in the long run, humane, empowering alternatives can be more effective and affordable.

Listening to a Focus Group of Psychiatric Survivors

In spring 2018, MindFreedom held a focus group of psychiatric survivors to hear what they felt most helped them speak up about their lives. The focus group ended by discussing what empowering alternatives for mental well-being supported them the best to record and share their stories.

MindFreedom focus group with David Oaks, Spring 2018.

Here are the top choices, in no particular order:

· Service projects for others

· Access to and participation in nature

· Activism

· Dialogues

· Eating well and exercise

· Mutual support and sharing

· Trauma-Releasing Exercises

· Journaling

· Anonymity and pseudonymity

· Pets

· Steam rooms, massage, yoga, and other similar alternatives

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- · Access granted by the Internet
- · Traveling, multiculturalism
- · Access to Education
- · Good Counseling
- · Recognition of different narratives and realities
- · Values of empathy and bravery

All in all, participants said they felt the focus group was very helpful for them. Some requested that we hold future local groups. The takeaway is that the moment the focus group felt empowered and protected, they were able to speak out about their stories!

A Dissident Psychologist Puts Psychiatry on the Couch

Bruce E. Levine is a practicing clinical psychologist often at odds with the mainstream of his profession. He writes and speaks about how society, culture, politics, and psychology intersect.

We asked Bruce about his recent analysis of how the psychiatric survivor movement could be more powerful. Bruce said, "I recall that I had just seen a Star Wars movie when I wrote those Politics 101 pieces with First Order (the bad guys) vs. the Resistance (the good guys). So I used the terms 'First-Order Psychiatry' vs. 'Rehumanizing Resistance' (the good guys who are, of course, us!)."

Bruce E. Levine, psychologist

Bruce calls the main part of the mental health industry, especially the American Psychiatric Association and the psychiatric drug manufacturers, "First-Order Psychiatry." In a series of essays, **mindfreedom.org/first-order-psychiatry-resistance**, this rebel mental health professional suggests how those of us opposed to psychiatric oppression, the "Rehumanizing Resistance," can effectively fight this First-Order. *Here are some excerpts:*

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Bruce Levine and Tactics to Rehumanize and Resist

Grasping the political threat of the Rehumanizing Resistance to its existence, First-Order Psychiatry—the far more politically astute of the two camps—has historically tried to marginalize and destroy the Resistance. First-Order Psychiatry has multiple political strategies and tactics for dealing with threats to its authority from its critics.

When individual critics of First-Order Psychiatry are low-profile, the First Order has simply ignored and dismissed them. Blowing off low-profile critics is an effective political tactic, causing many such critics to feel helpless and give up, or become so frustrated and enraged that they are politically ineffective.

When critics are more high-profile, the First-Order has derided, slandered, and attempted to destroy them. First-Order Psychiatry has meted out retributions to critics even when their challenges are not directed at First Order's authority to determine mental illness but only at First-Order's treatment ineffectiveness.

First-Order Psychiatry's political arsenal is fueled by Big Pharma financial backing, enabling the First-Order to monopolize the media and exploit people's fears of the unfamiliar. This results in First-Order treatment domination, and it is the lack of informed choice to which the Rehumanizing Resistance battles against.

In addition to retributions for critics, First-Order Psychiatry has employed many other strategies that authoritarian institutions have utilized to stay in power. One example is co-opting (taking control of something that could potentially cost them power and use it for their own purposes). The First-Order has attempted to co-opt some of the language of the Rehumanizing Resistance; and it has attempted to co-opt the peer support movement by, at times, hiring ex-patients not as genuine peer supporters but to assist the First-Order to maintain control.

Unlike First-Order Psychiatry, the Rehumanizing Resistance has historically been politically naïve. So, the Resistance has often

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squandered its time, energy, and resources attempting to dialogue with the First-Order trying to reform it. It is politically naïve for the Resistance to attempt to reform the First-Order when the First-Order considers the Resistance to be an existential threat to the First-Order's survival and wants to destroy it. This naivety is part of why the Resistance repeatedly wins scientific battles but is losing the greater political struggle. One example is the defeat of the chemical imbalance theory: Ronald Pies, editor in chief emeritus of the *Psychiatric Times*, stated in 2011, "In truth, the 'chemical imbalance' notion was always a kind of urban legend–never a theory seriously propounded by well-informed psychiatrists." mindfreedom.org/psychiatry-today-brain-imbalance

The Resistance has relied on articulating scientific truths and moral principles such as the right to informed choice. Scientific truths and moral principles can be politically powerful but only so if utilized with political strategies and tactics.

It is naïve to think that truth and morality wins regardless of political savvy.

First-Order Psychiatry has Big Pharma and their big money, which exerts influence in direct and indirect ways over the politicians, the mainstream media, and the general public.

A strategic goal of the Resistance is overwhelming popular recognition of scientific truths as well as an embrace of the moral principle of informed choice. Only with this overwhelming popular support will the mainstream media and politicians challenge First-Order Psychiatry's claim as a legitimate authority in determining "mental illness," and challenge its "treatment" and control dominion.

The Resistance must utilize effective tactics to
· expose the general public to **scientific truths**;
· validate the **public's apprehensions** about First-Order Psychiatry;

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- expose the public to **rehumanized alternatives**;
- celebrate the principle of **informed choice**; and
- energize the public about the Resistance as a **human rights movement**.

There are many tactics to achieve this strategic goal.

Traditional, Personal, and Underground Politics

Traditional politics includes lobbying elected officials, which can be quite effective on issues when the public is already overwhelmingly on the side of the Resistance.

Personal politics can also be very powerful. Ex-patients "coming out" about their past experiences with First-Order Psychiatry to family, friends, and acquaintances is a powerful way to change outlooks.

Personal politics is also important for dissident mental health professionals within their clinical practice, with their students, and within their social circles. It can be very powerful when professionals inform others of First-Order Psychiatry's lies and deception.

There is a rich literature of underground tactics that have been effective in overthrowing oppressive regimes and institutions. Political theorist and sociologist Gene Sharp's classic ***From Dictatorship to Democracy*** (mindfreedom.org/dictatorship-to-democracy) used by freedom fighters around the world, describes nearly 200 "Methods of Nonviolent Actions." Sharp tells us that: "When one wants to bring down a dictatorship most effectively and with the least cost then one has four immediate tasks:

- One must strengthen the oppressed population themselves in their determination, self-confidence, and resistance skills;
- One must strengthen the independent social groups and institutions of the oppressed people;
- One must create a powerful internal resistance force;

· One must develop a wise grand strategic plan for liberation and implement it skillfully.

All these areas are relevant to the Resistance. For example, it is extremely important to strengthen "independent social groups and institutions," which authoritarian regimes will attempt to target and destroy.

Organizing: Taking Advantage of the Current Cultural Climate

Alliances and Coalitions

In addition to organizing, wise alliances and coalitions are also politically important to increase the base of support.

First-Order Psychiatry, fighting for its very survival in the 1970s, formed an alliance with Big Pharma creating the Psychiatric-Pharmaceutical Industrial Complex, a powerful force in maintaining the First-Order's power and influence.

Given First-Order Psychiatry's alliance with Big Pharma, the Rehumanizing Resistance will likely continue to be financially outspent, and so the Resistance must counter by grassroots base-building, which includes forming alliances and coalitions.

The Rehumanizing Resistance is part of a greater societal movement against coercion, oppression, and authoritarianism, and the Resistance is fueled by the energy of anti-authoritarianism and morality. A long-standing internal conflict within the Resistance is whether or not it should ally with organizations that are enemies of First-Order Psychiatry but who themselves have reputations for coercion, oppression, and authoritarianism.

The good news is that there are natural allies who, by reputation and reality, clearly oppose coercion, oppression, authoritarianism, and dehumanization.

Another natural ally for the Rehumanizing Resistance is the large group of people frustrated and angry by "assembly-line medicine"

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and physicians who fail to correctly diagnose their conditions but instead label them with psychiatric diagnoses. This group has been damaged and stigmatized by unscientific mental illness labels.

The Rehumanizing Resistance has many other natural allies who oppose coercion, oppression, authoritarianism, and dehumanization, and who become sympathetic to the cause when they see how pathologizing noncompliant people has resulted in de-politicization and a loss of activists.

Film and Media

The Rehumanizing Resistance has put a great deal of effort into writing and speaking about the lack of science in First-Order Psychiatry and its corruption by Big Pharma, as well as the immorality of the lack of informed choice; and the Resistance has wisely also increased its emphasis on rehumanized alternatives.

Exposures to First-Order Psychiatry's pseudoscience, corruption, and immorality, as well as to rehumanized alternative approaches are politically powerful—but only if larger numbers of people hear about this in ways that are easy to grasp.

Today, with technological innovations, well-made powerful films need not cost huge amounts of money. The recent documentary **Healing Voices** de-pathologizes, rehumanizes, and celebrates voice hearers. From my experience in two discussion groups following screenings of **Healing Voices**, the audience was inspired and energized to become activists in the Resistance.

Even more inexpensive to produce but capable of huge viewership are YouTube and similar such videos. Eleanor Longden's TED Talk "The Voices in My Head," which de-pathologizes and rehumanizes hearing voices, has been viewed by between three and four million people. View here: mindfreedom.org/voices-in-my-head-ted-talk

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Resistance Activists' Frustrations

Every human rights activist gets frustrated.

Harriet Tubman, slave abolitionist and herself a runaway slave, conducted multiple missions as an Underground Railroad conductor and also participated in the Union Army's Combahee River Raid that freed more than 700 slaves. Looking back on her career as a freedom fighter, Tubman noted, *"I freed a thousand slaves. I could have freed a thousand more if only they knew they were slaves."*

The reality is that in human rights struggles, it is only a minority within an oppressed group that has the energy and strength to fight to end oppression.

Harriet Tubman by Horatio Seymour Squyer, 1848 - 18 Dec 1905 - National Portrait Gallery

Resistance activists must understand that the Resistance message of First-Order Psychiatry's pseudoscience, corruption, and illegitimacy is a message that can create painful dissonance for people who have placed their *doctrinal faith* in First-Order Psychiatry—resulting in a need to "kill the messenger." So, regardless of what the research states about how First-Order Psychiatry's labeling and biochemical explanations actually *increases stigma*, there will be First-Order apologists who continue needing to believe that these labels and biochemical explanations benefit them.

Resistance activists need to better differentiate between those open to scientific facts and those closed by doctrinal faith—and use their energy more wisely.

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Controversies and Divides

Controversies and divides are unavoidable, but allowing them to destroy a movement can be avoided. The Resistance's passion for truth and justice energizes the movement. However, the more *dispassionately* the Resistance approaches its internal controversies and divisions, the more likely it can keep them in perspective and not allow First-Order Psychiatry to "divide and conquer."

Resistance ex-patients can feel that Resistance dissident professionals, by virtue of "the letters after their names," are taken more seriously than they are. Resistance ex-patients can feel that their experiences as patients in the psychiatric system are not appreciated, and that they have less influence within the Resistance movement than dissident professionals. Helpful in recent years, the line between Resistance ex-patients and dissident professionals has blurred some: some ex-patients have become dissident professionals, such as psychologist Noel Hunter, author of ***Trauma and Madness in Mental Health Services***. Some dissident professionals have stated publicly that it is only by luck that they did not become patients themselves entangled within the psychiatric system, such as psychologist Paris Williams, author of ***Rethinking Madness***.

There is a great deal of anger in the Rehumanizing Resistance. Resistance ex-patients have anger over not being taken seriously by their families and psychiatric systems; and dissident professionals also have anger over not being taken seriously by colleagues and institutions; and all are angry at First-Order Psychiatry's corruption, abuse, pseudoscience, and oppression. Anger can help energize activism, but uncontrolled anger can be destructive to teamwork.

For more information about this analysis see many books by Bruce Levine, and his website: brucelevine.net. His most recent book is ***Resisting Illegitimate Authority: A Thinking Person's Guide to Being an Anti-Authoritarian—Strategies, Tools, and Models***.

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"The use of seclusion & restraint in mental health must end . . . Together we can reach this goal with WHO."

—Dr. Michelle Funk, Geneva, Switzerland, 2017.

The World Health Organization (WHO) is the official partner with the United Nations for international health, and WHO has officially endorsed some strong principles for human rights and mental health. WHO is publishing a series of modules to support human rights in mental health: **mindfreedom. org/who-quality-rights**. Their QualityRights Initiative "promotes strategies to end involuntary admission, involuntary treatment . . ."

Dr. Michelle Funk, coordinator of mental health policy and service development, World Health Organization

The below is reprinted with permission from Ms. Funk, before official release. The final version may be slightly different:

Excerpts from the *World Health Organization QualityRights Module:*

Advocacy Actions to Promote Human Rights in Mental Health

Activities will fall into a number of different categories. Below are general types of activities advocacy groups may conduct, and some examples of ways to conduct these. It should be noted that activities may fall into more than one category. Furthermore, the list is meant to serve as a guide rather than a list of prescriptive actions to be followed.

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Categories of activities can include, but are not limited to:

· Lobbying governments and politicians

· Creating and generating debate within communities

· Working with the media

· Using the courts

· Using international human rights mechanisms

These categories and some specific examples of activities that frequently fall within each category are described below.

Lobbying governments and politicians

Lobbying is a form of advocacy intended to influence governments and politicians to change legislation or policy or to persuade governments to invest more funding into mental health and related services. First it is important to identify the level of government which holds responsibility for the priority issue and the proposed solutions. Each level of government has its own policy development and legislative process; therefore, it is worth considering talking to everyone in the government that may be useful to the campaign. For example, someone who has very little political power or input today may be much more influential (and thus have the ability to help advance the campaign) in the future. It is helpful to know the people that the group is seeking to approach personalize the advocacy message and build relationships over time.

Useful ways to approach people can be:

· Attending meetings and spaces where relevant people can be met

· Inviting decision-makers for events organized by the group.

Public health and human rights issues frequently cross many sectors, so it may be relevant to raise issues with all the appropriate sectors and describe how their activities impact the health and wellbeing of the community. The group should find

opportunities where interests might align with decision-makers, for instance, reducing suicides in the local context might be a way to bring attention to services and supports needed. If and when appropriate, it may be useful to acknowledge any good work being done by decision-makers.

Relevant tools for lobbying governments and politicians include:

· Face-to-face meetings with politicians (or with ministers or their staff) and/or policymakers

· Writing letters or submissions to politicians

· Petitioning politicians

· Arranging a site visit or study tour

· Providing technical information and recommendations to policymakers (e.g. policy briefs)

These specific tools are discussed in further detail below.

Face-to-face meetings

Meeting with a policymaker in person can be one of the most effective ways to influence their position on a particular issue. However, be aware that these meetings can be difficult to arrange and may require a great deal of time and effort to organize. If given the opportunity to meet with a policymaker in person there are a few points to keep in mind:

· Schedule the visit in advance;

· Ensure that attending members are well prepared for the meeting and are knowledgeable about the issue and the individual policymaker;

· Ensure that the meeting is focused and organized (e.g., introduce oneself, the organization being representing, and the topic to be discussed);

· Listen, gather information, and do not become angry if the policymaker does not provide the desired response; and

· Express thanks and follow-up as needed.

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Written submissions

The aim of a submission is to influence policymakers in order to secure a favourable outcome on the advocacy issue. For example, an advocacy group may want to put forward a submission in response to a new or proposed government policy/law and may want to provide recommendations to improve the policy/law. Writing a submission allows advocates to express their ideas to the government, so that people can better understand how the new or proposed policy/law affects the community.

When writing a submission consider including:

- A short description of the advocacy group;
- Arguments and opinions on the issue at hand, for example the law or policy;
- Facts, examples and data; and
- Recommendations that include solutions and recommendations to address the identified problems.

Letters to politicians

Writing letters to policymakers can sometimes influence government policy. If all members of a network write to members of parliament at the same time, it can have an even greater impact. Keep the following points in mind when writing letters to politicians:

- Make it clear in the opening that the advocacy group has some knowledge of the individual being contacted.
- Keep letters as concise as possible in order to increase the likelihood that they will be read. One page or less is usually preferred.
- If possible, make letters as personal as possible. Avoid letters that are too "scripted."
- Cover only one issue per letter, as letters that address multiple issues may be less effective.
- Ask the individual being contacted to reply and directly ask if they will support the campaign's position.

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Arranging site visits

Arranging site visits can be an effective way to increase the awareness of policymakers, government officials, and other persons of influence of the importance of the priority issue. Site visits can serve a variety of functions depending on the advocacy group's goal and objectives. For example, site visits to several mental health and related services will provide an opportunity for policymakers to see firsthand the urgent need to improve the conditions of services—a situation that may otherwise go overlooked. These visits also create the opportunity for policymakers and officials to develop more personal, emotional connections with the priority issue, hence, opening up opportunities for increased support and possible funding. Site visits can also be used to showcase to government officials projects being carried out in the local community and their impact.

Creating and generating debate within communities

Creating and generating debate may be initiated for a wide range of advocacy issues. It can occur on a number of levels, including with the government and within the community. Often advocacy groups will use multiple activities in order to advocate on the same issue at different levels simultaneously in order to reach multiple sectors and capture the largest possible audience.

Relevant tools for creating and generating debate within communities include:

· Face-to-face communication and meetings with stakeholders

· Letters to the editor of a newspaper

· Serving on a committee

· Empowering community champions

· Holding events to increase public awareness (e.g., marches, walks, presentations)

· Holding public dialogues and forums (e.g., in schools, council meetings, churches)

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· Mobilization of groups (community members, public interest groups, etc.) to take action in support of policy change.

These tools are discussed in further detail below.

Face-to-face communication and meetings with stakeholders

Face-to-face meetings with stakeholders including with policymakers or other key people in the community can be an ideal opportunity to make the case for an advocacy issue. However, organising opportunities for face-to-face meetings often requires persistence and creativity since many stakeholders are difficult to reach and have limited time and availability. Some strategies that have proven successful include taking advantage of fortuitous situations, such as talking to a guest speaker after a public event or developing personal connections through networking.

Serving on committees

People with psychosocial, intellectual, and cognitive disabilities (and when appropriate their families/care partners and other advocates) can serve as members on many different types of committees at local and national levels. Examples of committees include: quality improvement committees in hospitals, mental health policy review committees, committees set up to monitor the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD), and committees for assessing human rights and quality conditions in mental health and related services. Offering to be a committee member can be a good opportunity to influence decision-making and to expand networking opportunities with people who may be able to assist with campaign activities.

United Nations Building by Ashitaka San https:flickr. com/photos/mononoke/225965762

Community champions

It may be useful to recognise and showcase individual "champions" when dealing with a specific issue. Champions can include celebrities, politicians, or well-regarded community members. The role of champions is to inspire and motivate others to join in a group's advocacy efforts. Community champions can be utilized in a variety of ways, including arranging an event or forum where they can publicly support the campaign issue or by profiling their story and support to the campaign on traditional media, websites, or other social media platforms.

A variety of events can be held in the community to increase the public's awareness of the advocacy campaign's goal. These events can include marches, walks, presentations, rallies, and/or fundraisers. Often, the event will receive more attention and therefore reach a wider audience if it is paired with important calendar dates, events, or announcements related to the priority issue.

For more information about the QualityRights activities, and the latest version of the training and guidance modules, see:
mindfreedom.org/who-quality-rights-activities

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Items for Action

· Become familiar with and distribute locally some of the original documents in the psychiatric survivor movement.

The US movement of psychiatric survivors held an annual gathering in the 1970s and the 1980s. From the beginning of their *Declaration of Principles*, here are the first three, plus #18 which translates mental health jargon into plain English:

The Tenth Annual International Conference on Human Rights and Psychiatric Oppression, held in Toronto, Canada, on May 14-18, 1982, adopted the following principles:

1. We oppose involuntary psychiatric intervention including civil commitment and the administration of psychiatric procedures ("treatments") by force or coercion or without informed consent.

2. We oppose involuntary psychiatric intervention because it is an unethical and unconstitutional denial of freedom, due proces, and the right to be let alone.

3. We oppose involuntary psychiatric intervention because it is a violation of the individual's right to control his or her own soul, mind, and body . . .

4. We oppose the use of psychiatric terms because they substitute jargon for plain English and are fundamentally stigmatizing, unscientific, mystifying, and superstitious.

Examples:

Plain English	Psychiatric Jargon
Psychiatric inmate	Mental patient
Psychiatric institution	Mental hospital/mental health center
Psychiatric system	Mental health system

Plain English	Psychiatric Jargon
Psychiatric procedure	Treatment/therapy
Personal or social difficulties in living	Mental illness
Socially undesirable characteristic or trait	Symptom
Drugs	Medication
Drugging	Chemotherapy
Electroshock	Electroconvulsive therapy
Anger	Hostility
Enthusiasm	Mania
Joy	Euphoria
Fear	Paranoia
Sadness/unhappiness	Depression
Visual/spiritual experience	Hallucination
Non-conformity	Schizophrenia
Unpopular belief	Delusion

For more about this and other historic documents, such as principles from the Insane Liberation Front, see: **mindfreedom.org/insane-liberation-front**

THE HIGHLANDER STATEMENT OF CONCERN AND CALL TO ACTION MARCH 25, 2000

Psychiatric survivors gathered for a national retreat. Here is their "Highlander Statement of Concern and Call to Action March 25, 2000": **mindfreedom.org/kb/highlander-2000**

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· *Find out more about raising funds for your human rights campaigns. The following document is based on successful fundraising by individuals with experience with mental health care:* **Fundraising for the Movement from National Empowerment Center:** For a great manual to guide your fundraising, especially for mental health consumers and psychiatric survivors, you may download a free seventy-four-page handbook, called ***Funding the Movement***, created by Vocal, Inc., Virginia's statewide network of mental health peers, and distributed by National Empowerment Center: **mindfreedom.org/vocal-funding-movement**

· To help you brainstorm about possible campaigns, check out the Free Online Tactics Service. The Centre for Victims of Torture has an online free service to help you brainstorm tactics. This can help you choose the right tactic for your human rights campaign: **newtactics.org/tactics**

· One of the main handbooks for tips about community organizing, including many blank forms and charts you can use for your campaigns, is this 401-page manual, now in its fourth edition (2010): ***Midwest Academy Manual: Organizing for Social Change***: **midwestacademy.com/manual**

· Find out more about peaceful styles of organizing, even during stressful campaigns. Some psychiatric survivor activists have benefited by learning about "nonviolent communication" or NVC. You can discover more here: **mindfreedom.org/nvc-model**

· Learn from a *"Model Anti-Murphy Act Letter"*
A major attack on the USA community of psychiatric survivors has been a piece of legislation that promotes coercive mental health and opposes empowerment. This "Helping Families in Mental Health Crisis Act" was passed by Congress in 2016. Even though the bill passed, opposition to

it can teach us all many important lessons. A model letter for fighting Murphy Bill: **mindfreedom.org/ndla-letter**

· Read about many successful campaigns via the website Mad in America: One of the most effective websites for challenging the mental health industry was inspired by author Robert Whitaker. You can find a lot of news there and dozens of blogs, including by David Oaks, former executive director of MindFreedom. MIA can be found here: **madinamerica.com**

· **David Oaks' personal blog**: **davidwoaks.com**

· **MindFreedom International** (MFI) has created a new website (as of this publication, 2019) that includes decades of resources. You can find personal stories, media articles, details about the Ray Sandford campaign, and much more: **mindfreedom.org**

· **ACLU Anti-Solitary Confinement Campaign:** There is a campaign among many prison justice and human rights groups to challenge the massive use of solitary confinement in the USA. One of the links: **mindfreedom.org/prisoners-rights-solitary-confinement**

· **Learn about powerful campaigns all around the world with Disability Rights International:** DRI is dedicated to promoting the human rights and full participation in society of people with disabilities worldwide. DRI is led by activists who champion advocacy for people labeled with either physical or mental disabilities: **driadvocacy.org**

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The Right to Be and Explore Our Differences

*by Ron Bassman, executive director of MindFreedom International*

It is an honor and a privilege for me, as the new executive director of MindFreedom International, to make a brief statement at the end of this organizing handbook that is designed to inform and promote genuine change in the thinking and treatment of those who experience extreme and anomalous states of emotions and consciousness.

Throughout this handbook you see a challenge to the plethora of quasi-medical/scientific misinformation, much of which is in collaboration with Big PHARMA's immoral pursuit of profit. Fear and false promises are the currency. Vulnerable people are being pushed into unconscionable treatments which essentially turn them into prisoners of the latest, greatest drugs and forced into hospitals where submission and compliance are the measures of successful outcomes.

I was committed to a mental hospital in 1966. Not being one to be compliant, even with high doses of Thorazine and Stelazine, I did not submit, and my refusal led to repeated stays in restraints and seclusion. After several months of being considered a hopeless schizophrenic, they brought out their biggest spirit-breaking weapon. For eight weeks, five days a week, I was put into an insulin-induced coma. Today, insulin coma therapy has been relegated to the same garbage heap as other treatments that were once declared miraculous and soon found to be not only ineffective, but harmful and dangerous.

So how far have we come from the 60s? What advances have we made in our understanding and knowledge of what is helpful and harmful to people who are struggling? I submit that the powers that be are still looking for simple biological, magic bullet explanations and refusing to acknowledge the immense mysteries of life. Even in psychotherapy with well-meaning, compassionate therapists, new therapies are continuously emerging and claiming to be the best for . . . you name the condition.
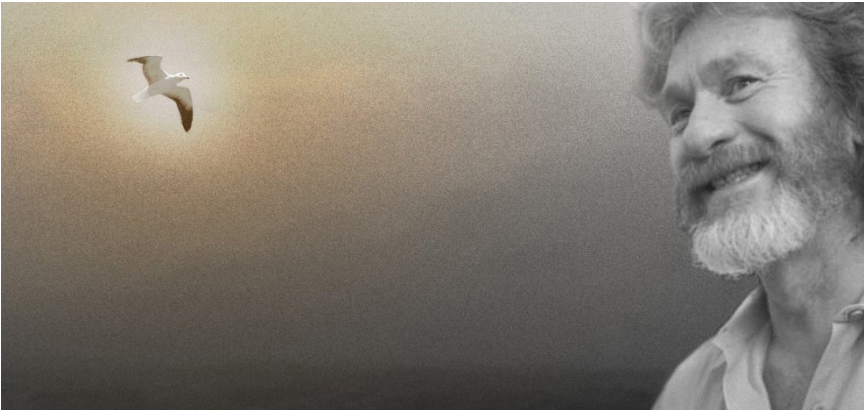
There is no one superior way to treat the diversity of so many who struggle to live their potential.

Today, January 25, 2019, as I write, we are awash in fear-based policies. Acts of what seem to be inexplicable violence solidify stigma and discrimination against people who are labelled with "serious mental illness." They become the scapegoats. Simple, inadequate explanations give reassurance that answers can be found within the individual as opposed to exploring the damaging impact of non-inclusive communities. Such exclusiveness gives rise to the preponderance of loneliness, shame, and feelings of inadequacy.

Yet, I do see progress. The progress and advances are coming from those of us who are experts by virtue of our experience. Slowly, we are beginning to be valued as collaborators in research and knowledgeable of what our fellow travelers want and need. As you have seen in our handbook, we are pushing forward. The road ahead is long and hard, but speaking from personal experience, it's worth the fight. Clearly, relationships, community, and commitment to our survivor mission–to make it a less painful journey for those who follow–advances our own recovery/transformation.

I remember when I first became aware of my identity as a psychiatric survivor, I was amazed and ecstatic by finding a community of like-minded people. For the first time I felt that I belonged. I urge each of you who have read this handbook to feel the power of belonging and how it can be transformative for you. Much work is needed to construct a fair and equitable society which values and finds ways to recognize and

GROVE

accommodate each person's strengths and weaknesses. There are no permanent conditions; we are always changing, developing, and/or regressing.

I still believe in a piece I wrote years ago in my book, **A Fight to Be: A Psychologist's Experience from Both Sides of the Locked Door:**

> "My ascent from madness to my present state of clarity and self-acceptance was and is a journey whose responsibility always resided within me. However, as I try to describe and share with others what wisdom I acquired, to aid others in their work, I acknowledge one element that I do not understand or take credit for, something that is named or interpreted according to one's unique beliefs and values as luck, fate, karma or God's blessing.
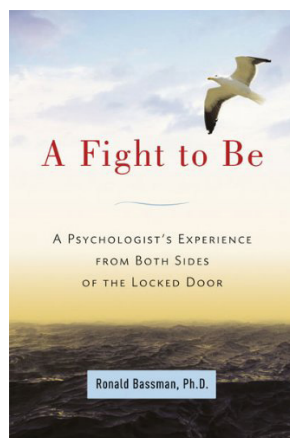
> I believe that as long as a person is alive, some seed of hope, some possibility is there waiting to be fertilized. Hope fights the fear, nurtures the courage and inspires the vision and the work required to resist giving up and accepting that your goals are unattainable. Deep in the recesses of our being there are safe sanctuaries, secure hiding places for never fully lost dreams. But sometimes they are hidden so well that we can no longer reach those parts of ourselves. The help we need may come from expected and unexpected sources."

In conclusion, I affirm the words of the late Bella Abzug, outspoken activist and New York congresswoman: "Never underestimate the importance of what we are doing. Never hesitate to tell the truth. And never, ever give in or give up."

Ron Bassman

Acknowledgements

Primary writing credits:

- Sarah Smith, Project Coordinator, Voices for Choices, MindFreedom International

With contributions from:

- Alita Taylor, Open Dialogue practitioner and trainer
- David Oaks, cofounder MindFreedom International, owner, Aciu Institute, **davidwoaks.com**
- Emily Cutler
- John Herald, **john@ pugetsoundhearingvoices. org**

Illustrations:

- Daniel Conan Young
- Cover art by © Nancy Bright "The Passage"
- Nut, Tree and Grove illustrations by Mikayle Stole

Design and Layout:

- Mikayle Stole, **mikayle.com**

Copyediting:

- Stephanie Amargi
- Additional help with editing and content development was received from Harriet Cooke and Emily Cutler.

Advisers:

Help with editing and content development of this handbook was provided by Advisory Committee Members: Cindy Olejar (MindFreedom Seattle), David Oaks (cofounder MindFreedom), Jim Flannery (Flantascience), Mary and Jim Maddock (MindFreedom Ireland).

Steering Committee:

Steering Committee members who generously donated their time to provide overall guidance of the "Voices for Choices" project as well as help with editing and content development of this handbook are: Al Galves, Celia Brown, Janet Foner, Susan Musante, and Ron Bassman, all of whom serve on MindFreedom's Board of Directors.

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