

***Visioning a Recovery Oriented
Mental Health System***
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 Law Project for Psychiatric Rights
<http://PsychRights.Org>

Amalie Days
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Mental Health Recovery Stories
Jim Gottstein

In 1982, when I was 29, I got into a situation where I didn't sleep for days. I tried to do too much. I went psychotic. When I heard someone coming down the hall, I thought the devil was after me and jumped out of my father's second-floor window in the wee hours in my underwear (since I knew how to do a parachute landing fall, I really didn't think I would get hurt, and I didn't). After I was captured, I was taken to Alaska Psychiatric Institute (API) in a straight-jacket, and pumped full of a whole lot of Mellaril.

Prior to this, I was a practicing attorney. I had gone through college in three years at the University of Oregon by averaging 21 hours a term, rather than the normal 15 hours. After graduating from college I was admitted to Harvard Law School. Since graduating from law school, I had been practicing law in Anchorage. Before my episode I had never run into a situation where I couldn't do all the work that "needed to get done."

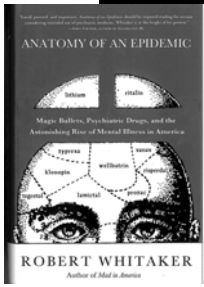
When I woke up in the hospital, still groggy from the medication that forced me (finally) to sleep, a young man was sitting in a chair at the foot of my bed with a clipboard. He asked me what day it was. I asked him how long I had been asleep. He wrote down that I didn't know what day it was. Things didn't get better from there. I was somewhat belligerent since I was used to being free and being able to make my own decisions. *Sometimes I would not go down to make them catch me. One time they didn't catch me before one hand hit*

**Psychiatric Symptoms: Responses to
Events/Experiences**

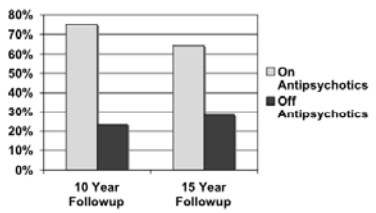
- Examples:
 - Multiple Personalities
 - Other Responses to Trauma
 - Mental Map Reorganization
 - Hearing Voices
 - Common Phenomenon
 - Mania
 - Icarus Project

**While Some People find
Neuroleptics Helpful . . .**

- Quality of Life Tremendously Diminished
- Cause Massive Amount of Physical Harm
 - Life Spans Now 25 Years Shorter in U.S.
- Greatly Reduce Recovery Rates
- 6-fold Increase in Mental Illness Disability Rate in U.S.
- Hugely and Unnecessarily Expensive
- Huge Unnecessary Human Toll



Psychotic Symptoms



Follow-up	On Antipsychotics (%)	Off Antipsychotics (%)
10 Year Followup	~75%	~25%
15 Year Followup	~65%	~30%

The schizophrenia patients who stayed on antipsychotics long-term were much more likely to continue to suffer from psychotic symptoms. Source: Martin Harrow and Thomas Libby: "Factors Involved in Outcome and Recovery in Schizophrenia Patients Not on Antipsychotic Medications: A 15-year Multifollow-up Study." *The Journal of Nervous and Mental Disease*, 195 (2007):406-414.

**Anti-Depressants Contributing to
Serious Mental Illness Diagnoses**

- Depressed Patients Convert to Bipolar Disorder Diagnosis on Anti-depressants at 7.7%/yr (3 times greater)
- Anti-depressants Have Made Bipolar Far More Disabling

The Transformation of Bipolar Disorder in the Modern Era

	Pre-Lithium Bipolar	Medicated Bipolar Today
Prevalence	1 in 5,000 to 20,000	1 in 20 to 50
Good long-term functional outcomes	75% to 90%	33%
Symptom course	Time-limited acute episodes of mania and major depression with recovery to euthymia and a favorable functional adaptation between episodes	Slow or incomplete recovery from acute episodes, continued risk of recurrences, and sustained morbidity over time
Cognitive function	No impairment between episodes or long-term impairment	Impairment even between episodes; long-term impairment in many cognitive domains; impairment is similar to what is observed in medicated schizophrenia

This information is drawn from multiple sources. See in particular Huxley, N. "Disability and its treatment in bipolar disorder patients." *Bipolar Disorders* 9 (2007): 183-96.

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First Hand Accounts of Psychiatric Experiences Are Invaluable

- On Our Own, by Judi Chamberlin
- A Fight to Be, by Ron Bassman
- How to Become a Schizophrenic, by John Modrow
- 5150: One Who Flew Into the Cuckoo's Nest, by Kathi Stringer



Freud's Taboo, by Francesca Spiegel

Recovery – JG Definition

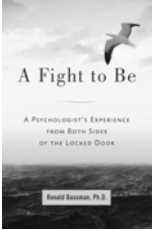
Getting past a diagnosis of mental illness to a point where a person enjoys meaningful activity, has relationships, and where psychiatric symptoms, if any, do not dominate or even play a major role in their life.

Recovery: Responsibilities and Roadblocks, by Jim Gottstein,
<http://akmhweb.org/recovery/RecoveryResponsibilitiesRoadblocks.pdf>

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Expertise of Successful Peers Should be Recognized

- Many examples of recovery from "incurable" mental illness.
- Unique ability to relate to people going through the same thing.
- Also some Mental Health Professionals Get It – They Listen to and Learn from (ex)Users.




Many Others

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Proven Alternatives to Coercion & Drugs

- Open Dialogue (Finland)
- Soteria (US & Switzerland)
- Runaway House (Berlin)
- Ionia (Alaska)
- Peer-Run (everywhere)
- Personal Ombudsman (Sweden)
- Second Opinion Society (Canada)
- Others- Alternatives Beyond Psychiatry



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Five-Year Outcomes for First-Episode Psychotic Patients in Finnish Western Lapland Treated with Open-Dialogue Therapy

Patients (N=75)	
Schizophrenia (N=30)	
Other psychotic disorders (N=45)	
Antipsychotic use	
Never exposed to antipsychotics	67%
Occasional use during five years	33%
Ongoing use at end of five years	20%
Psychotic symptoms	
Never relapsed during five years	67%
Asymptomatic at five-year followup	79%
Functional outcomes at five years	
Working or in school	73%
Unemployed	7%
On disability	20%

Source: Seikkula, J. "Five-year experience of first-episode non-affective psychosis in open-dialogue approach." *Psychotherapy Research* 16 (2006):214-28.

The Soteria Project

Study

First-episode schizophrenia patients treated conventionally in a hospital setting with drugs versus treatment in the Soteria House, which was staffed by non-professionals and involved no immediate use of antipsychotic medications. Results are from 1971-1983 cohorts, with 97 patients treated conventionally and 82 patients treated in Soteria House.

Results

- At end of six weeks, psychopathology reduced comparably in both groups.
- At end of two years:
 - Soteria patients had better psychopathology scores
 - Soteria patients had fewer hospital readmissions
 - Soteria patients had higher occupational levels
 - Soteria patients were more often living independently or with peers

Antipsychotic Use in Soteria Patients

76% did not use antipsychotic drugs during first six weeks
42% did not use any antipsychotic during two-year study
Only 19 % regularly maintained on drugs during follow-up period

J Nerv Ment Dis 1999; 187:142-149
J Nerv Ment Dis 2003; 191: 219-229

Recovery Principles

- Hope
- Someone believes in you
- You have to take responsibility for your own mental health and behavior
- You have to learn to recognize your symptoms.
- You have to learn what works for you.
- If it isn't voluntary it isn't treatment
 - Force is Counterproductive
- Different things work for different people
- Unsuccessful Attempts Part of Recovery Process
- Diagnoses of Limited Benefit/Mostly Harmful works for you.

Results to be Expected

- At Least Double the Number of People Who Recover fully. Should be at least 2/3rds to 3/4ths.
- Eliminate Much Suffering from Psychiatric Confinement and Compulsory Drugging
- Dramatically Improve the Lives of Many
- Dramatically Reduce Amount of Government Expenditures