

Testimony Feb. 6, 2014 on Vermont Bill 287
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Thank you for giving me this opportunity to give input on Bill 287. I assume that I have about 15 minutes to speak on these very important issues facing the citizens of the state of Vermont, so by necessity I will not be able to go into the great detail that this topic deserves. However I am hopeful that I can meaningfully contribute to the discussion. Having family, who have lived for many generations in Brattleboro, makes it even more personally important for me to contribute to this process of creating a strong array of services for people in need.

First by way of introduction, I will tell you about my experience as both a person who was diagnosed and treated for schizophrenia and as a licensed psychologist who has been working in the field for more than 4 decades. In 1966, I was hospitalized for 6 months and again was hospitalized in a state hospital for another 6 months in 1969. Since 1971, I have taken no psychiatric medication, nor have I been in any other form of treatment. My work with people with serious mental illness and the contributions I have made to the field has been recognized by the American Psychological Association (APA) in the form of a presidential citation. I have served two terms on the APA Experts Taskforce on Serious Mental Illness. I have written articles in peer reviewed journals and published the book, *A Fight to Be: A Psychologist's Experience From Both Sides of the Locked Door*. My most recent article, "Never Give Up" was published in the peer reviewed journal *Psychosis* and received an award as the best article of that year. My professional employment includes: being the executive director of a 7 county comprehensive mental health center; working as a contracted consultant for 9 years with the NY State Office of Mental Health where I worked with diverse programs, some of which were, evaluating the services at the 17 state hospitals and outpatient facilities, developing and training peer specialists, and providing support and education to self help groups.

Because of my good fortune and the help that I received in transforming my experience, I have felt an obligation and a calling to do all that I can to make it possible for others to overcome their experience of mental illness.

Today there are major developments in the field of serious mental illness. Recovery once thought impossible for disorders such as schizophrenia has been proven wrong by a significant number of researchers - notable is the landmark research conducted by Courtenay Harding in Vermont.

Harding, C. et al. (1987). The Vermont longitudinal study of persons with severe mental illness, I. Methodology, study sample, and overall status 32 years later. *American Journal of Psychiatry*, 144:718-728

In [Empirical Correction of Seven Myths About Schizophrenia with Implications for Treatment](#), by Courtenay M. Harding, Ph.D., and James H. Zahniser, *ACTA Psychiatrica Scandinava*, 1994: 90 (suppl 384): 140-146. These Studies have consistently found that half to two thirds of patients significantly improved or recovered, including

some cohorts of very chronic cases. The universal criteria for recovery have been defined as no current signs and symptoms of any mental illness, no current medications, working, relating well to family and friends, integrated into the community and behaving in such a way as to not being able to detect having ever been hospitalized for any kind of psychiatric problems. Some of the other long-term longitudinal studies:

Bleuler, Manfred (1974). The long-term course of the schizophrenic psychoses. *Psychological Medicine*, 4, 244-254

Huber, G., Gross, G., Schuttler, R.. (1975). Long-term follow-up study of schizophrenia. *Acta Psychiatrica Scandinavica*, 53, 49-57.

Ciampi, L. (1988). *Psyche and Schizophrenia*. Harvard U. Press, Cambridge, MA.

Tsuang, M., Woolson, R., and Fleming, J. (1979). Long-term outcome of major psychosis. *Archives of General Psychiatry*, 36: 1295-1301.

DeSisto, et al. (1995). The Maine and Vermont three decade studies of serious mental illness. *British Medical Journal of Psychiatry* 167: 338-342.

Pertaining to bill 287 - the speeding up and making it easier for individuals to be forced to take medication against their wishes in non emergency situations - I point to credible short and long term research which shows that there are persons that do better without medication. This is not to say that there are no instances in which medication is helpful. However, it is clear from research, that each individual must be carefully evaluated regardless of diagnosis. Within the diagnosis of schizophrenia, there are those who can benefit from taking medication short term and those that are harmed. It has been clearly established that even short term use of medication, can for some, cause irreversible physical disabilities. The choice to use medication needs to be carefully evaluated, rather than be used as a one size fits all formula. Research has emerged that shows that the delay of implementing a medication regimen does not result in harm to the patient.

I am aware that there is a Soteria project being developed in Vermont. Having myself worked on several projects with Loren Mosher who developed the first Soteria, I would like to point out some of the research conclusions.

During the 1970s, the head of schizophrenia studies at the NIMH, Loren Mosher, conducted an experiment that compared non-drug treatment to drug treatment, and he reported better outcomes for the non-drug patients. See, e.g.: Mosher LR and Menn AZ. *Soteria: An Alternative to Hospitalization for Schizophrenia*. In JH Masserman (Ed), *Current Psychiatric Therapies*, (Vol. XIV). New York: Grune and Stratton, Inc., pp. 287-296, 1974. Menn AZ and Mosher LR. *The Soteria Project. An Alternative to Hospitalization for Schizophrenics: Some Clinical Aspects*. In J Jorstad and E Ugelstad (Eds), *Schizophrenia 75*. Oslo, Norway: Universitetsforlaget, pp. 347-372, 1976. Mosher LR and Menn AZ. *Dinosaur or Astronaut? One-Year Follow-Up Data from the*

Soteria Project. In M Greenblatt and RD Budson (Eds), "A Symposium: Follow-up of Community Care". American Journal of Psychiatry, 133:8, 919-920, 1976. Mosher LR and Menn AZ. Lowered Barriers in the Community: The Soteria Model. In LI Stein and MA Test (Eds), Alternatives to Mental Hospital Treatment. New York: Plenum Press, pp. 75-113, 1977.

Loren Mosher, "[Community residential treatment for schizophrenia: two year followup](#)," *Hospital and Community Psychiatry*, 29 (1978), 715-723; Mosher, "[The treatment of acute psychosis without neuroleptics: six-week psychopathology outcome data from the Soteria project](#)," *International Journal of Social Psychiatry*, 41 (1995), 157-173; Mosher, "The Soteria project: twenty five years of swimming upriver," *Complexity and Change*, 9 (2000), 68-73.

In Berne, Switzerland Dr. Moser's results are validated:

[The Pilot Project Soteria Berne: Clinical Experiences and Results](#), Luc Ciompi, Hans Peter Dauwalder, Christian Maier, Exixabeth Aebi, Karl Trütsch, Zeno Kupper and Charlotte Rutishauser In this study, Switzerland researchers duplicate Mosher's results and find "patients who received no or very low-dosage medication demonstrated significantly better results."

I would like to add my personal experience to the above cited research. In 1970 after being discharged from the hospital and having lost two years of my memory, with the aid of a psychiatrist my medication was gradually reduced and after about 8 months I was medication free. In 1970 medication was not seen as an automatic panacea for everyone, so I was able to withdraw from my medication with the aid of a psychiatrist - at that time it was much easier to receive that kind of help from a professional. I now believe that I would not have ever gotten to the place where I am now if I was forced to continue taking psychiatric drugs.

Today, Soteria is not the only program that has shown itself to be successful. In New York City, there is a NYSOMH sponsored program called Parachute which is modeled after the successful Parachute program in Sweden.

[Acta Psychiatr Scand.](#) 2002 Oct;106(4):276-85.

One-year outcome in first episode psychosis patients in the Swedish Parachute project.

[Cullberg J](#), [Levander S](#), [Holmqvist R](#), [Mattsson M](#), [Wieselgren IM](#).

OBJECTIVE: Implementing a system designed to treat first episode psychotic (FEP) patients.

RESULTS: Psychiatric in-patient care was lower as was prescription of neuroleptic medication. Satisfaction with care was generally high in the Parachute group.

CONCLUSION: It is possible to successfully treat FEP patients with fewer in-patient days and less neuroleptic medication than is usually recommended, when combined with intensive psychosocial treatment and support.

As to Parachute NYC :

It provides options for people having a psychiatric crisis, i.e. emotional/mental health problems that make it difficult to manage without help. Instead of going to a hospital, Parachute NYC offers rapid access (within 24 hours) to home-based treatment and crisis respite centers where people can stay in a calm, supportive environment.

<http://www.nyc.gov/html/doh/html/ment>. The [Parachute NYC promotional video](#) is available on YouTube and via the [DOHMH website](#)

Last mentioned of the innovative programs, I cite Finland's "Open Dialogue." Its success has been rigorously evaluated.

Bola, J.R. , Lehtinen, K. , Cullberg, J. & Ciompi, L. (2009). Psychosocial treatment, antipsychotic postponement, and low-dose medication strategies in first episode psychosis. *Psychosis: Psychological, social and integrative approaches*.1(1).4-18.

Bola, J.R. , Lehtinen, K. , Aaltonen, J. , Rääköläinen, V. , Syvälahti, E. & Lehtinen, V. (2006). Predicting medication-free treatment responders in acute psychosis: Cross-validation from the Finnish need-adapted project. *The Journal of Nervous and Mental Disease*. 194(10). 732 - 739.

To make involuntary treatment synonymous with starting medication flies in the face of our emerging knowledge about psychosis and its treatment. We now are certain that full recovery is possible. We know that despite the usefulness of medication, we also know about the physical damage and the negative effects on recovery. We have learned that because of the exclusive use of medication in circumstances where other interventions could have worked, we have an every growing population of chronic patients whose cost is becoming more and more prohibitive.

Currently I serve on APA's Recovery to Practice committee which is now 5 years old. "As a part of the federal government's efforts to promote recovery for all Americans affected by mental illness and/or addiction, in May 2009, SAMHSA announced its [Recovery to Practice \(RTP\) Initiative](#). The RTP Initiative is designed to hasten awareness, acceptance, and adoption of recovery-based practices and builds on SAMHSA's definition and fundamental components of recovery." I saw the above mentioned principles listed in Vermont bill 114.

I am giving my testimony here today in hopes that Vermont will continue to move forward rather than backward and give the citizens of Vermont the best possibility of realizing their potential for living lives of quality and productivity. Mental illnesses are complex phenomena which are highly resistant to quick and simple solutions. Force drives people away from seeking treatment. Research sponsored by the state of California, "The Well-Being Project" authored by Jean Campbell and Ron Schraiber, was unequivocal in demonstrating that once people are forced into treatments not of their choosing, they avoid mental health services.

I would like to close by sharing with you a passage in my book that addresses my thoughts and feelings about my own recovery.

"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 them in their own 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 or unexpected sources."

Thank you!