Testimony
House Human Services Committee
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Thank you for inviting me to speak today.

I am Chief Medical Officer, Howard Center and Clinical Associate Professor of Psychiatry at the University Of Vermont College of Medicine. I came to VT 23 years ago and spent my first two years working at Vermont State Hospital before moving to Howard Center. Prior to that I was on the faculty of University of Pittsburgh and I worked for five years on a locked inpatient unit that specialized in the treatment of people diagnosed with schizophrenia. More recently, I was a local principal investigator for the NIMH sponsored Recovery After an Initial Schizophrenia Episode (RAISE) Early Treatment Program, a research study for people experiencing a first episode of psychosis.

In addition to this experience, I have spent a number of years re-evaluating our standard use of antipsychotic drugs. This has led me to research and seek training in non-pharmacologic treatments. I studied for two years at the Institute for Dialogic Practice in Northampton, Massachusetts where I learned about Open Dialogue and related approaches where drugs are not considered essential in the treatment of psychosis and have begun to use this approach in my work at Howard. I also had the opportunity to work for nine months as a consulting psychiatrist to Pathways Soteria Vermont. This is a program for people experiencing psychosis where drugs are not considered essential to their treatment. For the past five years, I have worked with a number of my patients who have elected to taper and in some cases discontinue their drugs and I have presented this result at several APA meetings.

When I came to Vermont from Pennsylvania 23 year ago, I was shocked at the legal process. In Pennsylvania, it would take up to one week to give a person drugs against his will. This happened after a rather perfunctory hearing and a request to a colleague to render a second opinion approving the use of drugs. In Vermont it took months and involved long legal proceedings. I thought at the time that this was a waste of limited resources. I did not understand why Vermont was so suspicious of my good intentions and medical knowledge.

But over time, I have come to believe that caution is warranted.

I will try to make four main points today:

1. Our diagnostic systems are not refined enough to allow us to know who will respond to which kind of treatment.
2. It has been axiomatic in psychiatry that antipsychotic drugs are essential in the treatment of psychosis and I believe there is adequate data to allow us to challenge that proposition.

3. The antipsychotic drugs are not quite the miracle drugs they are often purported to be.
4. There are increasing concerns about the effects of antipsychotic drugs over the long term and this may be having more of an impact on who is spending long periods of time in our hospitals than the refusal to take these drugs.
5. There are non-pharmacologic ways of helping people who are psychotic. Because we have had such a drug-centric approach to treatment, non-pharmacologic approaches are not adequately employed.

Our ability to arrive at a psychiatric diagnosis has not advanced much in the course of my career. Our understanding of the underlying nature of these problems has mostly resulted in deepening our appreciation of the complexity of neural function. A recent study that was heralded in the press as showing a big breakthrough in the understanding of schizophrenia found that multiple gene sites involved in what is called "pruning" increased one's risk of being diagnosed with schizophrenia. While fascinating, what did not receive attention is that this new finding accounted for only a 4% increased risk of developing psychosis. These reports tend to suggest that it is best to understand schizophrenia solely as something that happens inside the brain independent of life experiences. Perhaps this is true for some but we now have an increasing understanding of the ways in which traumatic life experiences – such as poverty, social isolation, bullying, violence, and other forms of abuse - can result in the many of the neurological changes in the brain described as explaining psychosis.

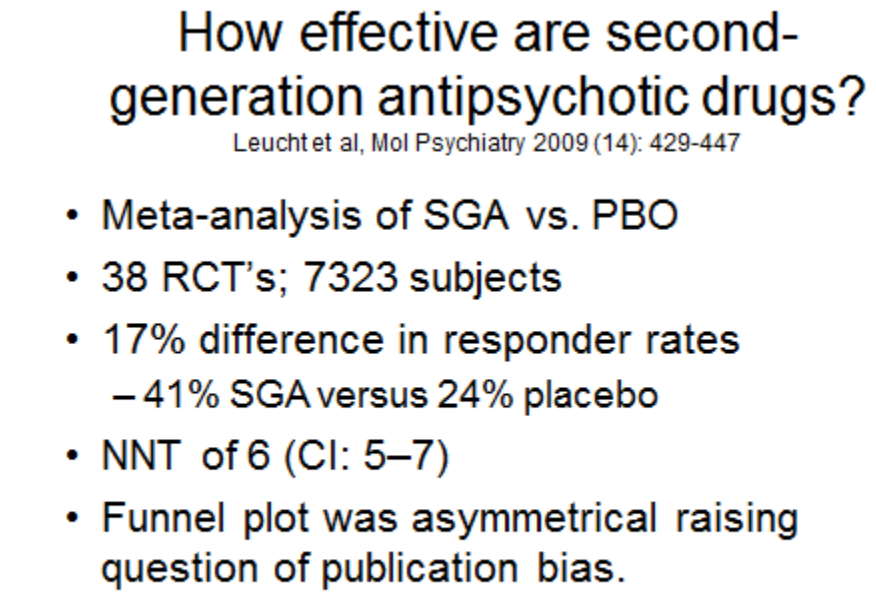
We have tended to think of those conditions that are "brain problems" as most amendable – and maybe only amendable – to drug treatment. We tend to think of those problems that we consider as "psychological" or "environmental" as most amenable to non-pharmacologic treatments. But these are false distinctions. We are in constant interaction with our environment. It is almost impossible to tease this apart and get to root causes of the problems we encounter in clinical practice. The vulnerability to environmental stress makes us all vulnerable to the many problems that beset humans but it also brings us hope since the environment can change and the brain can recover.

What are antipsychotic drugs? When they were first introduced, they were called major tranquilizers. The French physician who introduced them to the psychiatric hospitals did so after he noticed that they caused indifference. As recently as 2009, a major US psychiatry textbook notes that normal volunteers who take these drugs experience "feelings of dysphoria, paralysis of volition, and fatigue." (unhappiness, lack of drive) These drugs can cause tremors, muscle spasms, involuntary motor movements, weight gain, diabetes. There are good reasons why people would be reluctant to take them.

Yet, for most of my career, I thought that drugs were essential and the delay in treatment was not at all helpful. This notion came from the following sources:

a. Efficacy of the drugs: When the antipsychotic drugs were first used, it seemed to be helpful for many people who took them. However, if you look at current meta-analysis on efficacy they still all favor antipsychotic

drugs. However, the effect size of recent studies is much lower than is generally acknowledged.



b.
SGA=second generation antipsychotic
PBO=placebo
RCT=randomized control trial
NNT=number needed to treat (how many people need to take the drug for one person to benefit

Other recent studies, show only modest reductions of symptoms in people who take the drug as compared to those who take placebo. One study of people over 40 who were followed for two years, found no effect of drugs on any outcome measure.

On a pragmatic level, I would argue that many people who are in hospitals for extended stays are there because the drugs are not effective in reducing symptoms. In some instances they once were and the declining effect of the drugs over years, while not entirely relevant to this hearing, has been a strong focus of my interest over the past few years. I reviewed the 8 HC clients who are currently in hospital on EE or court ordered observation. Two are refusing drugs that I believe were helpful in the past. Five, however, are on drugs and were on them at admission but experience limited benefit. (One was off drugs but started them after admission.)

c. Duration of untreated psychosis: There has been a hypothesis in the field for over 20 years that delaying the use of antipsychotic drugs results in worse outcome. Researchers had noted that in the early studies, the group who was put on placebo did not catch up to the group who had been given active drugs even after the study ended. Richard Wyatt, an influential psychiatrist, wrote a paper on this in 1993 and looked at other studies that

he thought suggested that delaying drug treatment was harmful. This idea- a hypothesis – quickly became part of the accepted wisdom of our field. I have reviewed this literature and taken into account more recent studies. I do not think this hypothesis has been supported by ongoing research. While early intervention seems to be helpful, this intervention does not need to include drugs.

Association between the duration of untreated psychosis and short- and long-term outcome in schizophrenia

Pentilla, et al
Schiz Res 2013, 143 (1); 3-10

- Studied a large Finnish cohort from 1966
- 10 and 20 year outcomes
- 89 identified cases followed
- Hypothesis: longer DUP predicts worse outcome

DUP: Finnish Study

- Longer DUP associated with longer first hospitalization and higher risk of re-hospitalization in the short-term (first 2 years)
- Longer DUP associated with **decreased risk of disability pension, less time in hospital, more time at work in the long-term outcome** (first 10 years).
- "The results do not provide evidence for the assumed long-term association between longer DUP and poorer outcome. On the contrary…longer DUP may even associate with better clinical and occupational long-term outcomes."

Duration of Untreated Psychosis and Outcome of Schizophrenia

Haan et al,
Schizophrenia Bulletin, 29(2):341-348,2003

- Compares DUP and DIPT.
- When controlled for other variables, DUP no longer appeared to be significantly associated with negative symptoms.
- Longer DIPT had a higher probability of negative symptoms at 6 years independent of the influence of DUP, duration of treated psychosis, age at onset, and gender.

DUP=duration of untreated psychosis where treatment =drugs
DIPT=delay in psychosocial treatment

Most early intervention programs have moved away from the notion that introducing drugs early is beneficial. In Australia, where they have done the most work on this, they no longer recommend early intervention with drugs. At the very least, we can say that it is far from settled that delaying treatment causes irrevocable harm.

I have come to have many concerns about the anti-psychotic drugs. There is growing evidence that taking them continuously over many years may not maximize recovery. There are many studies that support this conclusion. In one important and recent study published in JAMA Psychiatry in 2013, over 100 individuals with first episode psychosis, after 6 month stabilization period with drugs, were randomized to either take the drugs continuously or only when symptoms recurrent. At 7 years, the group on intermittent drugs had a 40% recovery rate as compared to a 17% recovery rate in those who were maintained on drugs continuously.

As I have had increasing concerns about our current drug centered system of care, I have studied non-pharmacologic treatments.

The international Hearing Voices movement in which voice hearers help each other to make sense of and live with their voices and to understand the ways in which the voices are an experience to be understood as opposed to be eradicated is just one piece of evidence that, for some, non-pharmacologic interventions are helpful. We have begun to implement this approach in some of the DA's and we have an intensive training planned for next month.

Another approach is Open Dialogue from Northern Finland. This is a paradigm of care that involves the individual and his family. They do not consider drugs an essential element of care and they try to avoid using them. In other ways, however, they share many of the values we hold dear in VT and they embody many principles of recovery:
Hope
Self-determination
Flexibility of services
Families included in an open and respectful way.
Peer involvement (now being piloted here and in the UK)

In 5 year outcome studies of people experiencing a first episode of psychosis, only ~ 20% of people are on drug and only about 30% have even been exposed to drugs. Yet, only 19% of their group is on disability. This is dramatically different from even the best first episode programs in the US.

There is another reason to mention Open Dialogue. It holds an appeal to people with lived experience in the mental health system, family members, and those clinicians who have had some exposure to this way of working. You all have had enough experience of the many battles in this field to know that a treatment approach with such wide appeal is uncommon.

I have personally witnessed dramatic improvement in people who have taken these drugs – even under force. I work with people where I have come to the conclusion after many years, that I have no way to be of help other than to offer these drugs even under force. However, I also witness less positive outcomes. This is such a serious and intrusive act on a person. When this topic comes up, brave people who have been on the sharp end of the needle come forward. They are angry. They are not so sanguine about leaving the decision up to the well-intentioned psychiatrists. I know folks like this, too. Some people come out of this experience angry, frightened, and alienated and I have in the past at least taken some comfort in knowing that we had a vigorous legal process in place. Their stories are as true as the stories from psychiatrists who talk about people who ask – after the fact – "Why did you take so long?" People who are labeled with psychiatric conditions are often poor and less well-educated than the doctors, lawyers and judges who hold the power in the system. One thing I did not appreciate when I was a young psychiatrist who was baffled by VT's legal system is how much power even with the best laws is given to those with economic and educational privilege. Gov. Shumlin mentioned in an interview that is was cruel to withhold treatment. I think it is cruel to deprive people – who often have so little - of their rights to a fair hearing.

A final note. This plan is supposed to save us $5,000,000. If it goes forward, can we invest $1,000,000 in Open Dialogue? There is a group in VT who is already piloting this. We would like to go further. We believe VT could be on the forefront of implementing a progressive, humane, and respectful treatment for our citizens and we believe we might ultimately save the system money by diverting people from a life of long-term disability.

Sandra Steingard, M.D.
Brief bio:
Sandra Steingard, M.D. is Chief Medical Officer, Howard Center, Burlington, Vermont, USA and Clinical Associate Professor of Psychiatry at the University Of Vermont College of Medicine. For over 25 years her clinical practice has primarily included patients diagnosed with schizophrenia and other psychotic illnesses. She was a local principal investigator at a NAVIGATE site for the NIMH sponsored Recovery After an Initial Schizophrenia Episode (RAISE) Early Treatment Program, she studied for two years at the Institute for Dialogic Practice in Northampton, Massachusetts, and she worked for nine months as a consulting psychiatrist to Pathways Soteria Vermont.

She is on the Boards of the Foundation for Excellence in Mental Health Care and Mad In America Continuing Education. She is also on the board of National Alliance of Mentally Ill - Vermont from whom she received an Exemplary Psychiatrist Award in 1996. She was named to Best Doctors in America in 2003. She recently helped to create the Critical Psychiatry Network - North America. She writes a blog called *Anatomy of a Psychiatrist* on the website "Mad in America Science Psychiatry and Community", www.madinamerica.com.

In recent years, Dr. Steingard has been invited to give grand rounds and lectures around the US as well as in South America and Australia.

References:
I write a blog on topics related to psychiatric care. These are links to blogs that go into more detail on topics I addressed today.
http://www.madinamerica.com/2015/10/slow-psychiatry-integrating-need-adapted-approaches-with-drug-centered-pharmacology/
http://www.madinamerica.com/2015/08/a-network-meeting-in-north-america/
http://www.madinamerica.com/2013/03/optimal-use-of-neuroleptic-drugs-introduction/
http://www.madinamerica.com/2013/03/optimal-use-of-neuroleptic-drugs-part-2/
http://www.madinamerica.com/2013/04/optimla-use-of-neuroleptics-part-3-duration-of-untreated-psychosis/
http://www.madinamerica.com/2012/08/anosognosia-how-conjecture-becomes-medical-fact/