May 8, 2017

Oregon Senate Human Services Committee Hearing on HB 3262

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Today I am speaking for myself as an internal medicine physician and a geriatric psychiatrist as well as a very concerned citizen of the great state of Oregon and an advocate for those with mental illness and other behavioral disorders.

Madam Chair and Senators,

Thank you for allowing me this opportunity to testify against HB 3262. If I had known about this bill when it was discussed in the House I would have testified then. I have grave concerns about the language that is used in this bill, the broad reach of this bill, its amorphous qualities and the unintended consequences that I see worsening the lives of those who live in or need adult care homes, assisted living facilities and residential care facilities. The people who will be most harmed by this bill are those with mental illness. This is a group of people who already face significant stigma. This bill will continue this stigmatization and make it worse. I also believe that there is also an unfunded mandate that this bill involves that was missed when the fiscal impact statement was written.

First, let me point out that Linda Kirschbaum of the Oregon Health Care Association mentioned my name in her testimony in support of this bill. She was summarizing some of the work that OHCA has done with the Oregon Partnership to Improve Dementia Care (OPIDC). Neither I nor the OPIDC were involved in developing this bill. The OPIDC does not have a position for or against this bill. I fear that this may not have been clear in her testimony.

I wanted to make sure that you know that the 4 medication/classes of medications that cause the most emergency department visits and hospitalizations for older adults are: Warfarin/coumadin, Insulin, blood thinners such as Aspirin/clopidogrel/plavix and Oral hypoglycemic medications – diabetes medicines like metformin, glucophage, glipizide etc. *Budnitz, DS, et al.* ***Emergency Hospitalizations for Adverse Drug Events in Older Americans.*** *N Engl J Med. 2011;365:2002-2012. 365:2002-2012DOI: 10.1056/NEJMsa1103053.* The other large group of medications that is involved with significant and increasing health related harm are opiates especially when they are combined with other central nervous system depressants such as benzodiazepines or valium type drugs. https://www.cdc.gov. If the goal of this bill is to protect vulnerable Oregonians around prescription medications then working on improving education and training around these most dangerous of medications would be the place to start.

HB 3262 asks for a person-centered assessment and treatment plan for people living in community based care settings. This is certainly reasonable and is already in the regulations. It also mandates regular medication reviews which are also already in the regulations. However, HB 3262

contains the assumption that all psychotropic medications should only be given when nonpharmacological interventions have been trialed and then failed. This is just not true for all psychiatric illnesses. There are times when one is treating symptoms that this is true but not in every case or even in most cases. When a person has had multiple recurrent episodes of major depressive disorder and have recovered with medications, it is not right to trial non-pharmacological interventions first. When a person has bipolar disorder, and is stable until they develop sleep problems and then they need to start a medication to improve their sleep, this person should not be trialed on nonpharmacological interventions first. I can review multiple cases of real Oregonians who survived both situations only by taking appropriate medications. I can also review cases where people did not have access to medications and suffered relapses that took weeks, months or even years before they recovered. I also have worked with people who suffered relapses and were never able to enter remission of their illness again. There are times when a medication is the correct answer and time is of the essence. Additionally, competent adults have the right to refuse nonpharmacological interventions just as they can refuse medications. Many, though not all, older adults prefer to trial a medication first in addition to those where it is clinically indicated first.

We can all agree that some interventions including medications (of all types including psychiatric medications) are prescribed for the wrong person or in an inappropriate amount. Some medical interventions including prescription medications are not monitored closely enough. Some interventions including medications have side effects. Nontreatment also has "side effects" or consequences. Sometimes side effects are worse than the symptoms or illness one is treating. However, we already have rules and regulations in place if there are licensed providers who are willfully acting negligently. If that is the concern, then these are the statutes that need to be revised and this is the system that needs to be addressed. HB 3262 potentially places additional burdens on the care of every person who resides in community based care rather than addressing the cases where there are concerns.

The parts of the bill that refer to 2 doses of a medication are very confusing to me. The framework of regulating 2 doses of a medication makes the most sense in an acute care situation such as a hospital. It does not make sense in a community based care setting. There are no licensed nurses on duty 24/7 in community based settings. Providers are not visiting people daily in community based settings. I do not understand how putting into the statute this kind of detail will enable Oregonians to access the right care at the right time every time. One does not prescribe 2 doses of a medication except in the most unusual of circumstances.

The bill uses the definition of psychotropic medication from ORS 418.517 which is about children living in foster care. This legal definition of psychotropic medication is confusing and does not correspond to how psychotropic medications are thought of in medicine. Because ORS 418.517 is about children in a specific setting, it is not easily generalizable to older adults. Adults have many more mental illnesses (most major mental illnesses do not have an onset in childhood). Medications in the US are put in a category by the FDA when they are first approved. Even when clinical trials show that the medicine is safe and effective in other illnesses, the class of the medicine doesn't change. So, some medications that are chemically antipsychotics are in the class of drugs to treat nausea because that is what they were first used for while other medications such as some blood pressure lowering medicines are used to treat certain anxiety illnesses. Alternatively, some medications in the antidepressant classes are very effective at treating nerve pain or migraines. These types of nuances make the mention of psychotropic medication in a legal statute difficult to interpret in the medical sense. Additionally there is a definition

of psychotropic medications in the testimony that is different than the definition in some of the testimony making it unclear what the people who wrote the testimony understood about the bill.

One of my largest concerns around HB 3262 is the likely impact on the ability of those who need psychiatric medication to find housing. Already, if one is on an antipsychotic medication nursing homes are reluctant to accept you. This is multifactorial - due to the administrative burden, the public reporting of all antipsychotic prescribing and the star rating system. These systems do not reward you for appropriate use of medications, they just punish you for having people who are treated with these medications living in your facility. The easiest way for facilities to handle this is to not accept people in the first place. There is huge shortage of beds in both nursing homes and community based care especially Medicaid beds. Operators do not have to give a specific reason to not accept you, they just say "we do not have an appropriate bed" for this person or "we are not the right fit" for that person. HB 3262 will recreate this experience not just in nursing homes but now in all community based settings in Oregon.

I have also seen numerous people who were stable without side effects or symptoms of active mental illness taken off of their medications have a relapse of severe symptoms leading to an eviction. This is extremely common in a hospital setting. More than 50% of those who were referred to the Tuality Center for Geriatric Psychiatry during my 10 years there were not welcome in their previous living situation. Some people who suffer a psychotic episode are not able to recall what they said or did because their brain was not working well while they were well. But others do not forget what they saw and experienced. People have reported to me on more than one occasion that even if they were not evicted the staff and peers at the residence treat them differently, avoiding them and socially shunning them.

Major Depressive Disorder is the number one cause of disability in the world according to the World Health Organization. Depressive illness and anxiety disorders are extremely common in older adults. Many of the people living in Oregon in community based settings are appropriately treated with psychiatric medications. HB 3262 will place a large burden on both those who treat older adults in these settings as well as those who regulate them. There is no additional time or funds to pay primary care providers or others to review medications that have been legally ordered for those living in community based care. It is not clear what specific actions this bill is placing on prescribers. Responding to phone calls and faxes when there are specific issues and concerns makes sense but responding to these same communications when there is no perceived issue is confusing. Every prescriber already has certain legal and ethical duties when they write a prescription. If there are concerns about inappropriate prescribers then design a system to find them and either retrain or exclude them.

In reviewing the testimony submitted to the House when they were first considering this bill I noted several things. There was a reference to Robert Whitaker who is journalist from the east coast who has a very specific bias against antipsychotic medications and psychiatric medications in general. I am enclosing with my testimony a copy of an article by E. Fuller Torrey, MD who reviews some of the factual basis for Mr. Whitaker's viewpoint as well as some of the convincing evidence that disputes certain of his opinions. Dr. Torrey supports several of the issues Mr. Whitaker advocates on but he

points out a number of significant factual inaccuracies that Mr. Whitaker has amplified and repeatedly stated.

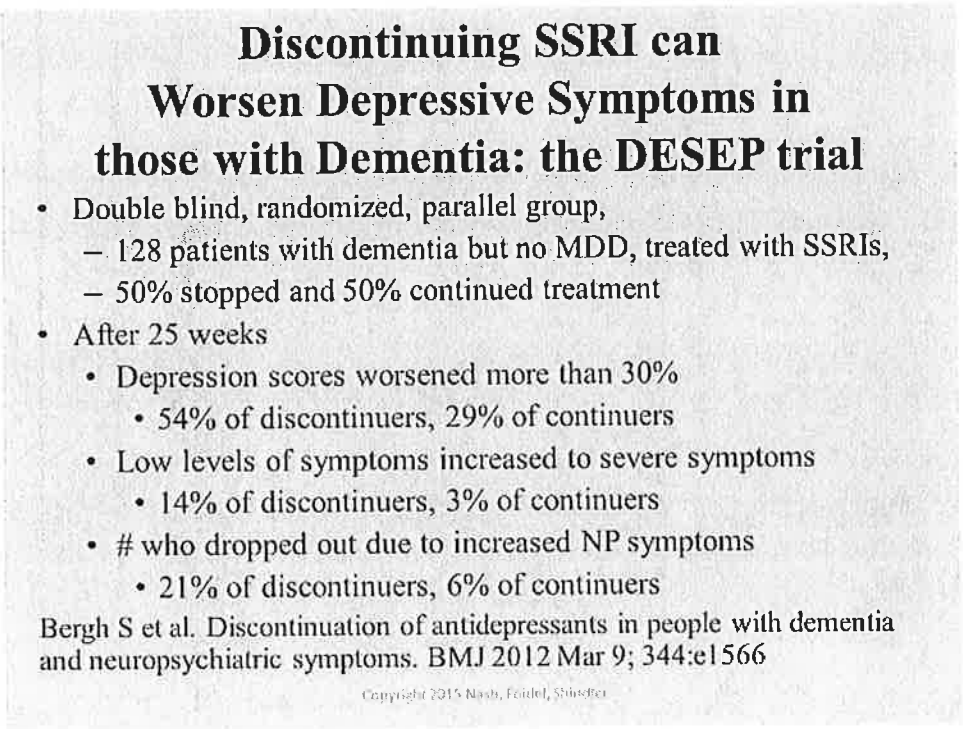
There is the assertion in the House testimony that "all psychotropic medications should be used in conjunction with, or as a last resort, after non-drug interventions. The use of these drugs should be reserved for severe symptoms that have failed to respond to non-drug strategies and treatments." There is no evidence that this is true. This may be true in certain circumstances-when treating behaviors that are not happening because of an accurately diagnosed mental illness for example. Behaviors in children and some behaviors in those with dementia come to mind but these are not the most common use of psychiatric medications. The most common use of psychiatric medications is to treat psychiatric illness. Much of the testimony of others around this bill concerns antipsychotic medication use in those with dementia. However, that is not what this bill addresses.

Much of the testimony for the house appeared to be focused on using psychiatric medications for those with dementia. This is likely not the largest group of people who use psychiatric medications in community based settings. There are some situations for people with dementia and behavioral disturbance where pharmacological interventions make the most sense and other situations where they do not. HB 3262 is not about people with a dementia diagnosis though. There are multiple references in testimony to associations in studies between medications and events such as death or falls. The problem with associations is that one does not know if they are cause or effect. For example, people with anxiety and depression have a high likelihood of falling-independent of any medication use. They also have a high likelihood of being on antidepressants. *Am J Geriatr Psychiatry. 2015 Oct;23(10):1016-28. doi: 10.1016/j.jagp.2014.11.004. Epub 2014 Nov 25. Cause or Effect? Selective Serotonin Reuptake Inhibitors and Falls in Older Adults: A Systematic Review. Gebara MA[1], Lipsey KL[2], Karp JF[3], Nash MC[4], Iaboni A[5], Lenze EJ[6].* At times this association is even more confusing. One study of ambulatory residents in a residential care population found that those who were at risk of wandering when treated with rispderidone 1 mg per day had a 70% reduction in falls compared to the placebo group though a higher dosage was associated with a higher risk of falls. *Am J Geriatr Psychiatry. 2004 Sep-Oct;12(5):499-508. Risperidone and falls in ambulatory nursing home residents with dementia and psychosis or agitation: secondary analysis of a double-blind, placebo-controlled trial. Katz IR[1], Rupnow M, Kozma C, Schneider L.*

Also in the testimony submitted to the House are references to potential overuse of psychiatric medications. I am including in my testimony some of the substantial evidence base reviewing the problem of undertreatment of psychiatric illness with medications. **I would propose that what we want is appropriate treatment, not too much and not too little.** I took care of a 78-year-old man who had been stable on a medium dose of thorazine for 20 years. I met him after an internal medicine physician stopped this medication while he was recovering in a skilled nursing facility (SNF) from a hospital stay. He begged the geriatric internist not to stop his medications but the internist believed he was doing the right thing; he also told me thorazine was an old medicine and should never be used anymore. I met the man because he became severely delusional about the staff at his assisted living facility (ALF) and began to threaten them. I restarted the man (who had a history of schizophrenia) on his medication and his symptoms resolved. However, he did not forget that the staff at the ALF were trying to kill him and he refused to return there. Despite having lived at this ALF for 7 years, he could never return there because even though his delusions resolved, his memory of people trying to kill him remained. Over the next 2 years he moved several times and then finally he died of unrelated causes. His quality of life never

returned to the level it had been prior to his SNF stay even though he physically recovered from the physical problems leading to the SNF stay.

Consequences of stopping medications in a carefully controlled setting:



Lucy

- Retired RN, first seen at age 78, moderate to severe Alzheimers, on SSRI escitalopram 10mg at initial evaluation
- "Is it time to shoot me?" repetitive, sad question + tearfulness
- I discussed dc of SSRI but daughter wanted to continue it, so we did
- Hospitalized with pneumonia and delirium at age 81, escitalopram stopped and not restarted at discharge
- Seen in follow-up 2 months later, perseverative question + tearfulness increased from ~5 times daily to >50 times daily
- Escitalopram restarted and again sadness decreased greatly

Other material:

From the National Alliance on Mental Illness

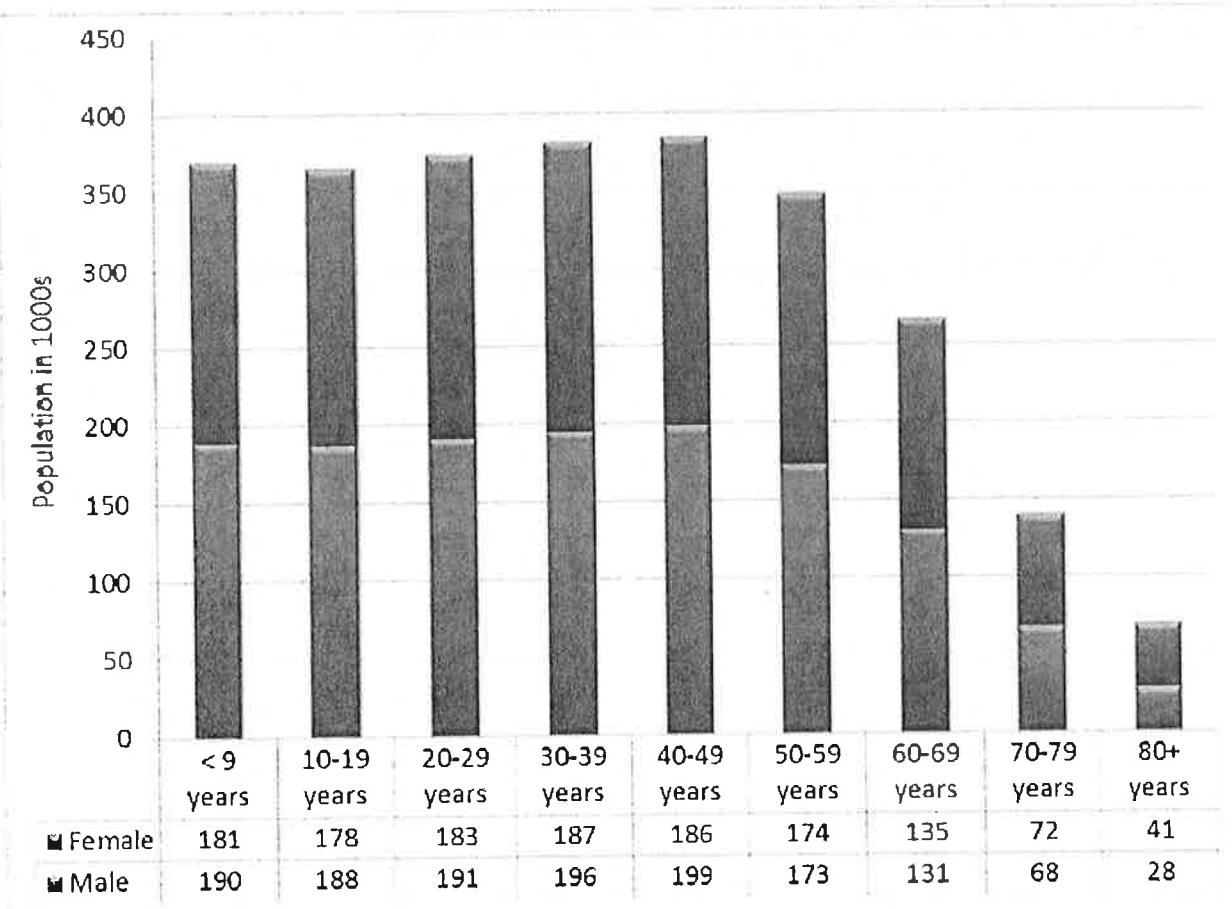
Mental health affects everyone regardless of culture, race, ethnicity, gender or sexual orientation. Less Than One-Third of Adults with Mental Illness Will Get Help in 2009 Mental Illness Awareness Week raises awareness about the availability of treatment for mental disorders; individuals face unemployment, homelessness and despair when they go untreated –

See more at: https://www.nami.org/Press-Media/Press-Releases/2009/Less-Than-One-Third-of-Adults-with-Mental-Illness#s

From the Administration on Aging Oregon Policy Academy State Profile

Oregon's Population OREGON POPULATION (IN 1000S) BY AGE GROUP

Oregon is home to nearly 3.9 million people. Of these, more than 1.3 million (34.4 percent) are over 50; nearly 770,000 (20.1 percent) are over 60; nearly 364,000 (9.5 percent) are over 70; and nearly 152,000 (4.0 percent) are over 80. The proportion of females rises steadily to 62.1 percent of the 80+ population.



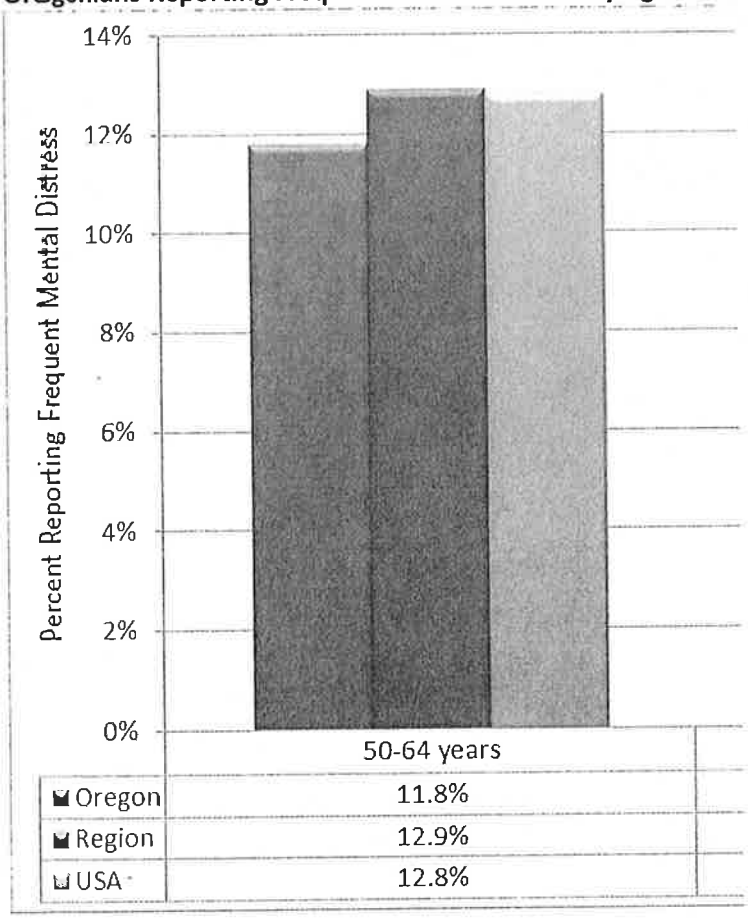
Source: U.S. Census Bureau, 2010

OLDER OREGONIANS REPORTING FREQUENT MENTAL DISTRESSBY BY AGE GROUP

People in the 65 and older age group are consistently less likely to report FMD than those in the 50-64 year group: 11 percent of Oregonians in the 50-64 and 6.7 percent in the 65 and older age group reported FMD. Confidence interval around national / regional and Oregon estimates were ± 0.2 and ± 2.0 percent respectively.

The following table provides a breakdown by age and gender:

Oregonians Reporting Frequent Mental Distress by Age and Gender



Source: Behavioral Risk Factor Surveillance System, 2011

https://aoa.acl.gov/AoA_Programs/HPW/Behavioral/docs2/Oregon.pdf accessed 5/3/2017

The Treatment Advocacy Center is a national 501(c)3 nonprofit organization dedicated to eliminating legal and other barriers to the timely and effective treatment of severe mental illness. The organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of innovative treatments for and research into the causes of severe and persistent psychiatric illnesses, such as schizophrenia and bipolar disorder. *The Stanley Medical Research Institute* is a fully integrated supporting organization to the Treatment Advocacy Center.

Public Psychiatric Beds in Oregon

A minimum of 50 beds per 100,000 people is considered necessary to provide minimally adequate treatment for individuals with severe mental illness. Like every state, Oregon fails to meet this minimum standard.

Beds in 2016	Beds in 2010	Beds lost or gained	Beds per 100,000 people	Census of forensic patients	% of all beds occupied forensic	State ranking in beds per capita
653	700	-47	16.2	439	67.2	9-10

(SOURCE: GOING, GOING, GONE: TRENDS AND CONSEQUENCES OF ELMINATING STATE PSYCHIATRIC BEDS, Treatment Advocacy Center, 2016)

Criminalization of Mental Illness in Oregon

Like every state in the nation, Oregon incarcerates more individuals with severe mental illness than it hospitalizes.

Total inmate population 2005	Estimated population of SMI inmates	Total psychiatric inpatient population 2004	Likelihood of incarceration vs. hospitalization
19,318	3,091	1,026	3.0 to 1

(SOURCE: MORE MENTALLY ILL PERSONS ARE IN JAILS AND PRISONS THAN HOSPITALS: A Survey of the States, Treatment Advocacy Center, 2010)

Criminal Diversion in Oregon

Criminal justice officials are responding to the criminalization of individuals with innovative programs designed to divert individuals with severe mental illness away from the criminal justice system. Two of the most promising programs are: mental health courts and crisis intervention training (CIT).

Percentage of population served by a mental health court	Percentage of population served by CIT	Combined average	Grade
54%	38%	46%	C+

(SOURCE: PREVALENCE OF MENTAL HEALTH DIVERSION PRACTICES: A SURVEY OF THE STATES, Treatment Advocacy Center, 2013)

http://www.treatmentadvocacycenter.org/browse-by-state/oregon accessed 5/3/2017

Fast Facts

Fast Facts

*Prevalence and Treatment Rates**

- **8.1 million** adults with schizophrenia or bipolar disorder mental illness (3.3% of the population)+

  5.4 million – approximate number with severe bipolar disorder (2.2% of the population), 51% untreated+

  2.7 million – approximate number with schizophrenia (1.1% of the population), 40% untreated+
- **3.9 million** – approximate number untreated in any given year (1.6% of the population)+

*Consequences of Non-treatment**

- **169,000** homeless people with serious mental illness**
- **383,000** inmates with mental illness in jails and prisons
- **50%** – estimated percentage of individuals with schizophrenia or bipolar who attempt suicide during their lifetimes
- **10%** – estimated percentage of homicides involving an offender with serious mental illness (approximately 1,425 per year at 2014 homicide rates)
- **29%** – estimated percentage of family homicides associated with serious mental illness
- **50%** – estimated percentage of mass killings associated with serious mental illness

* Numbers and percentages of US adults

†National Institute of Mental Health, 2016

**2015 Annual Homeless Assessment Report

http://www.treatmentadvocacycenter.org/evidence-and-research/fast-facts accessed 5/3/2017

Anxiety and Depression Association of America

Anxiety disorders are the **most common mental illness in the U.S.**, affecting 40 million adults in the United States age 18 and older, or 18% of the population. (Source: National Institute of Mental Health)

- Anxiety disorders are highly treatable, yet only about 1/3 of those suffering receive treatment.
- Anxiety disorders cost the U.S. more than $42 billion a year, almost one-third of the country's $148 billion total mental health bill, according to "The Economic Burden of Anxiety Disorders," a study commissioned by ADAA (*The Journal of Clinical Psychiatry,* 60(7), July 1999).
    - More than $22.84 billion of those costs are associated with the repeated use of health care services; people with anxiety disorders seek relief for symptoms that mimic physical illnesses.
- People with an anxiety disorder are three to five times more likely to go to the doctor and six times more likely to be hospitalized for psychiatric disorders than those who do not suffer from anxiety disorders.
- Anxiety disorders develop from a complex set of risk factors, including genetics, brain chemistry, personality, and life events.

Anxiety and Depression

It's not uncommon for someone with an anxiety disorder to also suffer from depression or vice versa. Nearly one-half of those diagnosed with depression are also diagnosed with an anxiety disorder.

Facts

Generalized Anxiety Disorder (GAD)

GAD affects 6.8 million adults, or 3.1% of the U.S. population.

Women are twice as likely to be affected as men.

Panic Disorder
6 million, 2.7%
Women are twice as likely to be affected as men.
Very high comorbidity rate with major depression.

Social Anxiety Disorder
15 million, 6.8%
Equally common among men and women, typically beginning around age 13.
According to a 2007 ADAA survey, 36% of people with social anxiety disorder report experiencing symptoms for 10 or more years before seeking help.

Specific Phobias
19 million, 8.7%
Women are twice as likely to be affected as men.
Typically begins in childhood; the median age of onset is 7.

Obsessive-compulsive disorder (OCD) and posttraumatic stress disorder (PTSD) are closely related to anxiety disorders, which some may experience at the same time, along with depression.

Obsessive-Compulsive Disorder (OCD)
2.2 million, 1.0%
Equally common among men and women.
The median age of onset is 19, with 25 percent of cases occurring by age 14. One-third of affected adults first experienced symptoms in childhood.

Posttraumatic Stress Disorder (PTSD)
7.7 million, 3.5%
Women are more likely to be affected than men.
Rape is the most likely trigger of PTSD: 65% of men and 45.9% of women who are raped will develop the disorder.
Childhood sexual abuse is a strong predictor of lifetime likelihood for developing PTSD.

Major Depressive Disorder
The leading cause of disability in the U.S. for ages 15 to 44.3
Affects more than 15 million American adults, or about 6.7 percent of the U.S. population age 18 and older in a given year.
While major depressive disorder can develop at any age, the median age at onset is 32.5
More prevalent in women than in men.

Persistent depressive disorder, or PDD, (formerly called dysthymia) is a form of depression that usually continues for at least two years.
Affects approximately 1.5 percent of the U.S. population age 18 and older in a given year. (about 3.3 million American adults).
The median age of onset is 31.1

Related Illnesses
Many people with an anxiety disorder also have a co-occurring disorder or physical illness, which can make their symptoms worse and recovery more difficult. It's essential to be treated for both disorders.

https://www.adaa.org/about-adaa/press-room/facts-statistics accessed 5/3/2017

OH SU Brain Institute

Sta tistics on Brain and Nervous System Conditions

Condition	National Prevalence	Data Source
Alzheimer's Disease	5,300,000	Alzheimer's Association: 2016 Alzheimer's Disease Facts and Figures
Anxiety Disorders	40,000,000	National Institute of Mental Health: Anxiety Disorders
Bipolar Disorder	8,500,000	National Institute of Mental Health: Bipolar Disorder Among Adults
Depression (Major)	18,200,000	National Institute of Mental Health: Major Depression Among Adults
Parkinson's disease	1,000,000	Parkinson's Disease Foundation: Statistics on Parkinson's
Schizophrenia	1.1% of U.S. Adult Population	National Institute of Mental Health: Schizophrenia
Substance Abuse Disorders	20,200,000	Substance Abuse and Mental Health Services Administration: Mental and Substance Use Disorders

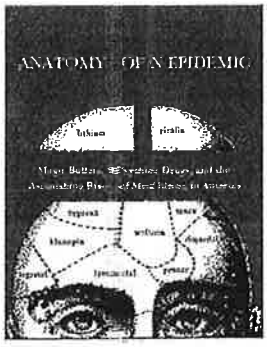
http://www.ohsu.edu/xd/health/services/brain/getting-treatment/diagnosis/disease-statistics.cfm

accessed 5/3/2017

Anatomy of a Non–Epidemic – a Review by Dr. Torrey

How Robert Whitaker Got It Wrong

Review by E. Fuller Torrey, MD
Treatment Advocacy Center founder



In 2010 Robert Whitaker published *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America* (New York: Crown Publishers). The book has circulated widely, in large measure due to Marcia Angell's surprisingly uncritical review of it in the *New York Review of Books* (Angell, 2011). In its 396 pages Whitaker got many things right, including criticism of the broad DSM diagnostic criteria for mental illnesses; the reckless prescribing of psychiatric drugs for children; and the prostitution of many psychiatric leaders for the pharmaceutical industry. Indeed, regarding the last, Whitaker may have understated the problem, based on recently released court documents detailing how the pharmaceutical industry secretly controlled the Texas Medication Algorithm Project (http://www.kxan.com/dpp/news/investigations/drug-firms-paid-independent-experts).

When it came to schizophrenia and antipsychotic drugs, however, Whitaker got it mostly wrong. He made so many errors it is difficult to know where to begin, so I will begin where he did. In his *Preface* Whitaker says that his research on the book began when he encountered "two research findings that just didn't make sense": a 1994 schizophrenia outcome study (Hegarty et al. 1994) and the World Health Organization (WHO) studies "which had twice found that schizophrenia outcomes were much better in poor countries."

diagnostic criteria and schizophrenia outcomes

Whitaker summarized the 1994 outcome study by saying that "outcomes for schizophrenia patients in the United States had *worsened* during the past two decades and were now no better than they had been a century earlier," and he later added that the worsened outcomes were due to the use of antipsychotic drugs. What the paper actually says, however, is quite different. It is an analysis of schizophrenia outcomes throughout the twentieth century, linking outcomes to diagnostic criteria. When a broad definition of schizophrenia was in vogue, outcomes were better but when a narrow definition was in vogue, outcomes were worse, as would be expected. The data showed a clear improvement in outcomes during the 1960s and 1970s following the introduction of antipsychotic drugs, then a worsening in the 1980s and 1990s. The authors attributed this to the introduction of a narrow definition of schizophrenia, requiring six months of symptoms to qualify for the diagnosis, in DSM-III introduced in 1980. They concluded "that diagnostic criteria have had a consistent and predictable impact on outcome before and during the era of modern biomedical therapeutics." The authors did not claim that the outcome of schizophrenia had actually worsened.

The two multi-country WHO schizophrenia outcome studies, which claimed that individuals with schizophrenia in developing countries had much better outcomes than those in developed countries, were relied upon heavily by Whitaker, both in this book and in his previous writings (Whitaker, 2004). Whitaker claimed that the patients in developing countries did better because they were less likely to be treated with antipsychotic medication. The authors of the WHO studies reported "a marked predominance of favourable outcomes in the centres in developing countries" and a "considerably more favourable [course] in developing countries" (Sartorius et al., 1986). These claims were heavily criticized at the time they were first published (e.g. Stevens, 1986) because it was alleged that the WHO centers in the developing countries had included many individuals who did not have true schizophrenia. Rather they had included many patients with acute reactive psychosis which has a much better outcome than true schizophrenia.

There is much evidence to support this criticism. For example, the second WHO study reported that "49% of the patients in the developing countries had an acute onset, and this was the case in only 26% of the patients in the developed countries." Consistent with this was the fact that 40% of the cases in the developing countries were initially diagnosed with an "acute schizophrenic episode" versus 23% of cases in developed countries. In addition, the inclusion criteria for diagnosing schizophrenia was very broad for these studies; for example, a patient could meet criteria for schizophrenia with a combination of "severe excitement" and "overwhelming fear" without having any delusions, hallucinations or thought disorder (Sartorius et al. 1986). Even more worrisome was the fact that a significant number of subjects in the developing countries were referred to the study by religious or traditional healers. All of us who have worked psychiatrically in developing countries have seen many acutely excited individuals with acute reactive psychosis, most of whom get well. This is the most probable explanation for the WHO findings.

The WHO claim of better outcomes for schizophrenia in developing countries has continued to be criticized over the years and has now been largely discredited. Cohen et al. (2008) examined 23 schizophrenia outcome studies in 11 low-and-middle income countries and concluded that there is "a need to reexamine the conclusions of the WHO studies." Messias et al. (2007) suggested that an increased mortality among the sickest patients in developing countries may have created an illusion that outcomes among other patients were better. And most recently Teferra et al. (2011) reported five years outcome data on 321 schizophrenia patients in rural Ethiopia with results sharply at variance with the WHO results. Faced with such criticisms, the authors of the WHO studies have recently modified their claims, stating that "we do not argue that the prognosis of schizophrenia in developing countries is groupwise uniformly milder" and acknowledging that "the proportions of continuous unremitting illness...did not differ significantly across the two types [developed and developing] of settings: (Jablensky & Sartorius 2008).

Schizophrenia Outcomes and Medication

The WHO studies raise the more general issue of schizophrenia outcome studies, an issue that is critical for Whitaker's thesis. It has been known for a century that approximately one-quarter of individuals who develop a schizophrenia-like psychosis will recover without treatment and not get sick again. For example, in 1938 Stalker reviewed 16 schizophrenia outcome studies and concluded that 22 percent of the patients had achieved complete or social remission, the latter meaning that the person had resumed employment. More recently Stephens (1978) analyzed 25 schizophrenia outcome studies in which follow-up had been for 10 years or longer. Although the percentages of good and poor outcomes varied considerably in the different studies depending on the diagnostic criteria used, consistent with the

findings of Hegarty et al. (1994) noted above, on average one-quarter of the patients recovered completely, one-quarter had a continuous illness, and the other half had intermediate outcomes between these two extremes. Stephens thus "emphasized that there are relatively benign and malignant forms of illnesses generally diagnosed as schizophrenia."

Since these schizophrenia outcome studies had been known for many years, it was a great surprise to many of us when the 2003 President's New Freedom Commission on Mental Health "discovered" that many individuals with schizophrenia do recover. It was a discovery of recovery, a classic example of finding something that had not really been lost. It suggested that the potpourri of political appointees who made up the Commission did not include anybody with any knowledge of the past studies.

This is directly relevant for Whitaker's book because he focuses much attention on studies in which some patients with schizophrenia recover without medication. One of Whitaker's favorite studies to support his thesis is a 20-year follow-up study of 70 patients (61 with schizophrenia and 9 with schizoaffective disorder) followed by Martin Harrow, a psychologist at the University of Illinois, and his colleagues. Harrow et al. (2012) reported that over the 20-year period 15 (21 percent) of the patients recovered and never thereafter needed antipsychotic medication. In addition, at each of the six follow-up assessments over the 20 years, between 7 and 12 additional patients were not taking antipsychotic medication, although some were taking antidepressants or other psychiatric medication (Harrow & Jobe, 2007; Harrow et al. 2012). Harrow et al. note that those patients not taking antipsychotics had either been taken off the medications by their treating psychiatrist or were "self-selected" and had taken themselves off medication. In terms of function, the individuals who were not taking antipsychotics were functioning better than those taking antipsychotics, as would be expected since the former group included the 15 patients who initially recovered.

On non-medication and recovery

Since the Harrow et al. study reported a schizophrenia recovery rate entirely consistent with previous follow-up studies and the fact that patients who are able to stop antipsychotic medication at least temporarily were functioning better, it is a completely unremarkable study. Whitaker, however, calls it "the best study of the long-term outcomes of schizophrenia in the United States" and discusses it four separate times in his book. Using tortured logic, he asserts that the Harrow et al. study proves that long-term antipsychotic use causes brain damage and is responsible for many of the symptoms of schizophrenia, when in fact the study does nothing of the kind. Harrow et al. even explicitly state that their study provides no evidence on "whether very long-term use of antipsychotic medication produces undesirable effects for some SZ [individuals with schizophrenia]."

Another study held up by Whitaker to demonstrate that individuals with schizophrenia who are not taking medication do better is Courtney Harding et al.'s Vermont outcome study. As Whitaker described it, among 168 patients with schizophrenia followed up 20 years after hospital discharge, "34 percent were recovered" which he claims is "a startling good long-term outcome." Whitaker attributes this outcome to the fact that "they all had long since stopped taking their medications." The original study stated that half of the patients were taking antipsychotics continuously or intermittently (Harding et al, 1987). Since the average age of these patients was 61, it is not surprising that many others had been able to discontinue medication and were doing well since it is known that the need for antipsychotic medication decreases with age for many patients. The other factor not mentioned by Whitaker is that Dr. George Brooks, the second author on the Harding et al. study and former director of the hospital, was known to be an extremely caring and conscientious psychiatrist who personally followed up his patients in the community. He was essentially a one-man ACT team. The important lesson from the Vermont study is thus not its outcome data, but rather the importance not only of continuity of care but also of continuity of *caretaker*, as described elsewhere (Torrey 1986).

Yet another study invoked by Whitaker to illustrate the importance of treating schizophrenia without antipsychotics is a treatment program in northern Finland covering a population of 70,000 people. The program was begun in 1969 by a Finnish psychoanalyst. Using "group family therapy," individual psychotherapy, a belief that psychosis "arises from severely frayed social relationships" and a philosophy of "no immediate use of neuroleptics," Whitaker claims that this group has achieved remarkable outcomes with 79 percent of first-episode patients being "asymptomatic" at the end of five years (p.340). He even claims that "schizophrenia is now disappearing from the region"(p.343). Most revealing and remarkable, however, is the fact that more than 40 years after this treatment program began, there are almost no publications describing its results and nobody in Finland or elsewhere has tried to replicate it. Robert Whitaker appears to be the person most impressed by it.

Whitaker clearly believes that schizophrenia should be treated without medication if at all possible. However he fails to focus any attention on the fact that on any given day in the United States half of all individuals with schizophrenia, or about one million people, are not being treated. This is a huge natural experiment to test his thesis. Many of these individuals are found in public shelters, sleeping under bridges, in jails, and in prisons. If Whitaker had spent more time in these settings observing the outcome of this natural experiment, instead of delivering lectures on his vision of the impending antipsychotic apocalypse, he would have written a very different book.

What SSI/SSDI Rates Say

Whitaker's main thesis is that antipsychotic drugs are responsible for causing many, if not most, of the symptoms of schizophrenia. It is a "drug-induced epidemic of disabling mental illness" (p.361). His exhibit A to prove his thesis is the number of individuals receiving SSI and SSDI disability for mental illness. In 1987 there were 1.25 million Americans receiving such disability, or 1 in every 184 Americans. By 2007 this number had increased to 3.97 million people, or 1 in every 76 Americans, more than doubling over the 20 years. During these years antipsychotic and antidepressant use increased markedly in the United States, which Whitaker claims is the cause of the increase in the disability numbers.

The number of individuals on disability for mental illness under SSI and SSDI has indeed increased alarmingly, but not for the reason proposed by Whitaker. One reason is that virtually all public psychiatric beds have been closed so patients previously living in state mental hospitals are now living on SSI and SSDI in the community. In 1987 there were still 107,531 state hospital beds available for the nation's 242.3 million people or 44.4 beds per 100,000 population. By 2007 the number of beds had been reduced to 37,376 for 301.6 million people, or 12.4 beds per 100,000 population. Almost all seriously mentally ill individuals who had become sick during that period had been put on mental disability on SSI and SSDI.

The other reason for the dramatic increase in SSI and SSDI disability numbers is that SSI and SSDI have become alternatives to welfare for poor and unemployed individuals who have any kind of psychiatric problem. During the Reagan administration there was an attempt to purge the SSI and SSDI roles of individuals who didn't really qualify. This attempt resulted in court suits, bad publicity, and it thus politically backfired on President Reagan. Since that time the federal government has made no serious attempt to restrict SSI and SSDI with the result that most people who apply are ultimately approved if they persist through the appeals process. Indeed, a small industry of social workers and lawyers has grown up to help people get SSI and SSDI disability. They advertise on billboards in low income areas and on the Internet. In fact, coincidentally on the day I was writing this review, I received an Internet solicitation from a firm in Omaha, Nebraska offering to help me "if you were denied your Social Security or Disability benefits, or you would like to know if you qualify for them." SSI and SSDI disability benefits are attractive; SSI currently pays $698 per month if you are single and $1,048 if you are married and SSDI pays more; the benefits continue indefinitely; and SSI eligibility also qualifies the person for Medicaid. It is thus no mystery why these disability programs have expanded so quickly.

The Dopamine Receptor Story

In addition to believing that antipsychotic drugs cause many, if not most, symptoms of schizophrenia, Whitaker thinks he knows how this happens. Almost forty years ago it was shown that when rats are given antipsychotic drugs, a subset of their dopamine-2 receptors markedly increase in number. Although it was not then, and still is not clear whether or not this also occurs in humans, it has led to a theory of supersensitivity psychosis. It is proposed that antipsychotic drugs cause an increase in the receptors, and when the drugs are stopped this causes symptoms that are identical to those of schizophrenia. This causes the person to be treated with more antipsychotics, causing a further increase in receptors, causing more symptoms when the drugs are withdrawn etc. Whitaker is correct that this could potentially be a serious problem, but at this point in time the reality of the problem in humans is unknown. That does not stop Whitaker from simply assuming its validity, as when he describes a patient who is "screaming and tearing at her hair" as being "deep into a withdrawal psychosis" (p.250). Whitaker does not say how he knows that this is a "withdrawal psychosis" rather than the symptoms of schizophrenia, a distinction that no professional has yet been able to make.

In fact, the dopamine receptor story is much more complicated than Whitaker described. The increase in rat dopamine receptors which can be caused by administering antipsychotic drugs can also be caused by administering caffeine, steroids, cocaine, amphetamines, by birth injuries, or even by social isolation (Seeman 2011). If rats, who have been administered amphetamines causing a marked increase in dopamine 2 receptors are then given antipsychotic drugs, this causes a decrease in the number of such receptors (Seeman 2008). It is not even known for certain how dopamine is causally related to the symptoms of schizophrenia. The recent finding that the parasite *Toxoplasma gondii*, which has been linked to schizophrenia in some studies (Torrey et al. 2008), can also produce dopamine (Gaskell et al. 2009), has further complicated dopamine's role.

What is perhaps most surprising in Whitaker's book, given his past career as a respected journalist, is his willingness to uncritically accept anything he has been told, as long as it fits his thesis and his wish to blame antipsychotics for everything except global warming. An example is his claim that in the 1970s "Loren Mosher was ousted from the NIMH for having run his Soteria experiment" (p. 304), an experiment in which some patients with schizophrenia were treated without drugs. Mosher at the time was the director of NIMH's Schizophrenia Research Branch. The loss of his position had nothing to do with Soteria but rather was due to other factors. Most important was the fact that the schizophrenia research field was moving strongly in a biological direction at the time, with the approval of a new NIMH director. Mosher did not view schizophrenia as a brain disease, a view that put him increasingly at odds with both NIMH and the vast majority of researchers. NIMH continued to support the evaluation of the Soteria experiment after Mosher's departure.

An example of Whitaker's attribution of all adverse events to antipsychotics is in his description of a woman who was treated with several antipsychotics. She later got ovarian cancer and, according to Whitaker, "it's possible that illness was related to the psychiatric medications" (p.214). On the contrary, multiple studies have reported that individuals with schizophrenia have a reduced risk of cancer, with some studies have even suggested that antipsychotic drugs have a cancer protective value (Wagner & Mantel 1978; Mortensen 1994; Caraillo & Benitez 1999). Similarly, when short on data Whitaker tends to invoke hyperbole to make his points: the use of antidepressants "routinely manufactures bipolar patients" (p. 181) and antipsychotics are causing "an astonishing medical disaster" (p. 193).

Schizophrenia Before Medications

So what does Whitaker believe about people diagnosed with schizophrenia? He never makes this clear but hints that he doubts that schizophrenia is a real disease. In his previous book, *Mad in America*, he described schizophrenia as a term "loosely applied to people with widely disparate emotional problems" and accused the medical profession of "minting 'schizophrenics' from a troubled cast of people." In that book he recommended that such individuals be treated with "love and food and understanding, not drugs." In the present book he recommends as treatment "rest, psychological therapies etc." (p.19). Other than reciting studies showing that antipsychotics change some brain structures, as would be expected from an effective medication, Whitaker completely ignores the more than 100 studies demonstrating brain changes in individuals before they have ever been treated with antipsychotics.

But if schizophrenia is largely a product of antipsychotic drug use, who were those millions of people in state psychiatric hospitals beginning in the early 1800s until antipsychotics were introduced in the 1960s? This question seems to perplex Whitaker and he has no good answer. He weakly offers an explanation put forth by Mary Boyle, an English psychologist and author of *Schizophrenia: A Scientific Delusion?* Citing a 1990 paper by Boyle, Whitaker claims that "many of Kraepelin's dementia praecox [schizophrenia] patients were undoubtedly suffering from a viral disease, encephalitis lethargica, which in the late 1800s had yet to be identified" (pp. 90-91). In fact, encephalitis lethargica is a well-defined syndrome which followed the 1917 influenza pandemic (Ravenholt & Foege, 1982). There is no evidence whatsoever that it existed prior to that time or continued beyond about 1930.

But *something* was going on in the nineteenth century to cause the number of insane persons, as they were then called, to increase markedly. As I detailed in my book *The Invisible Plague: The Rise of Mental Illness from 1750 to the Present*, the number of insane persons per 1000 population increased from approximately 0.5 per 1,000 in 1850 to 3.2 per 1,000 in 1950, a six fold increase. The largest percentage of these insane individuals had the disease we now call schizophrenia. The greatest irony of Whitaker's book, in my opinion, is that there really was an epidemic of schizophrenia, but it occurred a century prior to the introduction of antipsychotic drugs, claimed by Whitaker to have caused it. The reason why his book is weakest in discussing this period is because literally millions of individuals with schizophrenia were not treated with drugs, as he now advocates. The outcome of this lack of treatment was not pretty, as he is aware.

Anatomy of an Epidemic is not without merit, however. In addition to detailing the many wrongs of American psychiatry, it reminds us what good psychiatric practice should be regarding the use of antipsychotic drugs. Use them in as low a dose as possible for no longer than necessary. Patients with a first episode of psychosis should be taken off the drugs several months after they go into remission to ascertain whether they are among the subgroup of patients who will not need maintenance medication. As patients age their medication can often be reduced and sometimes discontinued. And we need better research to be able to identify which patients need which drugs, who will develop which side effects, and who no longer needs medication. As psychiatrists we shouldn't need to have a journalist remind us of these things; we should already be doing them.

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