

The Causes and Consequences of Our Failure to Treat Individuals with Severe Psychiatric Disorders

E. Fuller Torrey, MD
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This talk is available online at:

www.treatmentadvocacycenter.org/generalresources/documents/namiJune07.pdf

with links to pertinent studies.

The sad truth is that in many parts of the country, there is no mental health system.

Michael Fitzpatrick, 2007
NAMI Executive Director

Drugs don't work in people who don't take them.

C. Everett Koop, M.D.

Severe psychiatric disorders =

- Schizophrenia
- Schizoaffective disorders
- Bipolar disorder with psychosis
- Major depression with psychosis

I. How many individuals with severe psychiatric disorders are not being treated at any given time?

How many individuals are not being treated, cont'd

Approximately 50%

- Since there are, conservatively, 4 million individuals with severe psychiatric disorders in the United States, approximately 2 million are not being treated.

How many individuals are not being treated, cont'd

Approximately 50%

- Since there are, conservatively, 4 million individuals with severe psychiatric disorders in the United States, approximately 2 million are not being treated.
- This is equivalent to the metropolitan area population of Cleveland or San Antonio.

Click [HERE](#) for additional data

Why do people with severe psychiatric disorders not take medication?

The biggest single reason, confirmed in several studies, is that they do not think they are sick. They have limited or no awareness of their illness. In neurological terms, this is called *anosognosia*.

What is anosognosia?

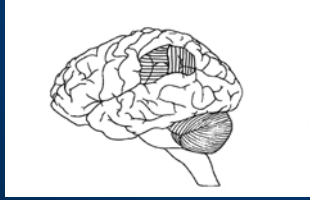
What is anosognosia, cont'd

- It is an impaired awareness of illness. It is also called *lack of insight*.

What is anosognosia, cont'd

- It is an impaired awareness of illness. It is also called *lack of insight*.
- It occurs in some individuals who have strokes or brain tumors in the right side of the brain. It appears to be caused by damage to the connections between the frontal lobe and the inferior parietal lobe.

Inferior Parietal Lobe



The supramarginal gyrus (BA40)
has vertical lines.

The angular gyrus (BA39) has horizontal lines.

What is anosognosia, cont'd

- It occurs in approximately 50% of individuals with schizophrenia and 40% of individuals with bipolar disorder. The lack of awareness may be partial or complete.

What is anosognosia, cont'd

- It occurs in approximately 50% of individuals with schizophrenia and 40% of individuals with bipolar disorder. The lack of awareness may be partial or complete.
- It is not the same thing as *denial*, which is psychological in origin. Anosognosia is neurological in origin.

What is anosognosia, cont'd

- It sometimes improves when the person is on medication.

What is anosognosia, cont'd

- It sometimes improves when the person is on medication.
- A very helpful book on anosognosia is:

Dr. Xavier Amador's
I'm Not Sick, I Don't Need Help.

Click [HERE](#) for additional data

Other reasons people with severe psychiatric disorders do not take medication

- Anosognosia
- Substance abuse

Substance Abuse

In one study, it was reported that “substance-abusing patients with schizophrenia were 13 times more likely than non-substance-abusing patients to be noncompliant with antipsychotic medication.”

Kashner TM et al. Family characteristics, substance abuse, and hospitalization patterns of patients with schizophrenia. *Hospital and Community Psychiatry* 1991;42:195-197.

Other reasons people with severe psychiatric disorders do not take medication

- Anosognosia
- Substance abuse
- Poor relationship between psychiatric staff and patients

Other reasons people with severe psychiatric disorders do not take medication

- Anosognosia
- Substance abuse
- Poor relationship between psychiatric staff and patients
- Medication side effects

Other reasons, cont'd

- Other
 - Cost of medication
 - Lack of access, e.g., in jail
 - Confusion and/or inability to remember
 - Lack of improvement
 - Stigma: “concerned about what others may think”
 - Quality of services: “not satisfied with available services”

Click [HERE](#) for additional data

II. Consequences of Non-Treatment

- Relapse, rehospitalization, and increased costs

Relapse, Rehospitalization, and Increased Costs

Individuals with schizophrenia with poor medication adherence are more than 3 times more likely to be rehospitalized within one year, compared to those with good adherence.

Weiden PJ et al. Partial compliance and risk of rehospitalization among California Medicaid patients. *Psychiatric Services* 2004;55:886-891.

Relapse, rehospitalization, and increased costs, cont'd

Individuals with schizophrenia with poor medication adherence had hospital costs in one year more than 3 times higher than those with good adherence.

Gilmer TP et al. Adherence to treatment with antipsychotic medication and health care costs among Medicaid beneficiaries with schizophrenia. *American Journal of Psychiatry* 2004;161:692-699.

II. Consequences of Non-Treatment

- Relapse, rehospitalization, and increased costs
- Suicide and self-mutilation

Suicide and Self-Mutilation

Among the approximately 29,000 suicides each year in the U.S., at least 5,000 individuals are psychotic at the time they commit suicide.

Suicide and self-mutilation, cont'd

A study of suicide among individuals with schizophrenia reported that "there were 7 times as many patients who did not comply with treatment in the suicide group as there were in the control group."

De Hert M et al. Risk factors for suicide in young people suffering from schizophrenia. *Schizophrenia Research* 2001;47:127-134.

Suicide and self-mutilation, cont'd

Self-mutilation is an uncommon but serious form of self-harm. In a study of 9 patients with schizophrenia who mutilated themselves (e.g., stab wound, partial removal of eye), 8 of the 9 were not on medication.

Sweeny S, Zamecnik K. Predictors of self-mutilation in patients with schizophrenia. *American Journal of Psychiatry* 1981;138:1086-1089.

Click [HERE](#) for additional data

II. Consequences of Non-Treatment

- Relapse, rehospitalization, and increased costs
- Suicide and self-mutilation
- Victimization

Victimization

Individuals with severe psychiatric disorders are vulnerable to exploitation and victimization.

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This is especially true if they are not taking medication and thus are more psychotic.

Victimization, cont'd

- Los Angeles: One-third of individuals in board-and-care homes "reported being robbed and/or assaulted during the preceding year."

Victimization, cont'd

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- Washington DC: One-third of women reported "at least one sexual assault while homeless."

Victimization, cont'd

- Los Angeles: One-third of individuals in board-and-care homes "reported being robbed and/or assaulted during the preceding year."
- Washington DC: One-third of women reported "at least one sexual assault while homeless."
- North Carolina: Eight percent had been the victim of a violent crime (assault, rape, or mugging) in the 4 months preceding their psychiatric admission.

Victimization, cont'd

- Pittsburgh: 15% were violently victimized within 10 weeks following psychiatric hospital discharge.

Victimization, cont'd

- **Pittsburgh: 15% were violently victimized within 10 weeks following psychiatric hospital discharge.**
- A National Crime Victimization Survey of 936 patients reported that more than one-quarter “had been a victim of a violent crime in the past year, a rate more than 11 times higher than the general population.”

Victimization, cont'd

- The importance of medication for reducing victimization was clearly demonstrated by a study in North Carolina. Individuals who were on outpatient commitment (and thus taking medication) were reported to be victimized approximately half as often as individuals not on outpatient commitment, some of whom were not taking medication.

Click [HERE](#) for additional data

II. Consequences of Non-Treatment

- Relapse, rehospitalization, and increased costs
- Suicide and self-mutilation
- Victimization
- Homelessness

Homelessness, cont'd

- A 2005 survey of the U.S. estimated that there were 744,000 homeless people; 439,000 of them were single individuals, and the rest were part of families.

Homelessness, cont'd

- A 2005 survey of the U.S. estimated that there were 744,000 homeless people; 439,000 of them were single individuals, and the rest were part of families.
- Multiple studies have reported that at least one-third of single homeless people have severe psychiatric disorders. Thus, there are between 150,000 and 200,000 homeless individuals with severe psychiatric disorders. This is equivalent to the population of Des Moines, Providence, or Salt Lake City.

Homelessness, cont'd

- In Massachusetts, 27% of patients discharged from a state hospital became homeless within 6 months. In a similar study in Ohio, the figure was 36%.

Homelessness, cont'd

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- A study of homeless mentally ill individuals reported that 28% of them got some of their food from garbage cans, and 8% used garbage cans as their primary source of food.

Homelessness, cont'd

- Almost all homeless people with severe psychiatric disorder are not being treated because we are respecting their "civil rights."

Homelessness, cont'd

- Almost all homeless people with severe psychiatric disorder are not being treated because we are respecting their "civil rights."
- One reporter commented: "It's as if we suddenly decided to respect the 'right' of Alzheimer's patients to wander wherever they please."

Homelessness, cont'd

- A Miami police officer commented: "Seeing another human being living like an animal in America, it just shouldn't be like that. It gets frustrating not being able to do anything legally to get help."

Click [HERE](#) for additional data

II. Consequences of Non-Treatment

- Relapse, rehospitalization, and increased costs
- Suicide and self-mutilation
- Victimization
- Homelessness
- Criminalization: jails and prisons

Criminalization, cont'd

- Approximately 10% of the nation's 2.2 million jail and prison inmates—or 220,000 individuals—have severe psychiatric disorders.

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Criminalization, cont'd

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- These 220,000 individuals are equivalent to the population of Akron, Madison, Richmond, or Tacoma.
- The Los Angeles County Jail, Chicago's Cook County Jail, and New York's Rikers Island Jail are, *de facto*, the nation's three largest "psychiatric hospitals."

Criminalization, cont'd

- In every county in the United States, the county jail holds more severely mentally ill individuals than the psychiatric unit of the county hospital.

Criminalization, cont'd

- In every county in the United States, the county jail holds more severely mentally ill individuals than the psychiatric unit of the county hospital.
- The vast majority of severely mentally ill individuals in jail are charged with misdemeanor crimes that took place because their psychiatric illness was not being treated.

Criminalization, cont'd

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- There is evidence that this problem is continuing to get worse. As NAMI's Mike Fitzgerald recently said, "the tragedy of criminalization is worse than ever before."

Criminalization, cont'd

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- There is evidence that this problem is continuing to get worse. As NAMI's Mike Fitzgerald recently said, "the tragedy of criminalization is worse than ever before."
- Read Pete Earley's recent book:

Crazy: A Father's Search Through America's Mental Health Madness

Click [HERE](#) for additional data

The "freedom" to be penniless, helpless, ill, and finally arrested, jailed and criminally committed is not freedom at all—it is abandonment. . . . The "liberty" to be naked in a padded cell, hallucinating, delusional, and tormented, is not liberty—it is a *folie à deux* between pseudo-sophisticated liberals and an unrealizing public.

Darold Treffert, 1982

II. Consequences of Non-Treatment

- Relapse, rehospitalization, and increased costs
- Suicide and self-mutilation
- Victimization
- Homelessness
- Criminalization: jails and prisons
- Violence and homicides

Violence and homicide, cont'd

- Among individuals with severe psychiatric disorders in NAMI families, 11% had physically harmed someone in the past year (1992 NAMI survey).

Violence and homicide, cont'd

- Among individuals with severe psychiatric disorders in NAMI families, 11% had physically harmed someone in the past year (1992 NAMI survey).
- MacArthur Violence Risk Assessment one-year prevalence of serious violence:

18% without substance abuse
31% with substance abuse

Violence and homicide, cont'd

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Violence and homicide, cont'd

- Treatment with antipsychotic medication reduces the incidence of violence by more than half.
- Homicides: individuals with severe psychiatric disorders who are not being treated are responsible for at least 5% of all homicides (studies range from 5% to 18%).
- In 2005, there were 16,192 homicides in the U.S. Therefore, almost 900 of them were attributable to individuals with severe psychiatric disorders.

Violence and homicide, cont'd

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Violence and homicide, cont'd

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 - Parents killed by children: 75% were severely mentally ill

Violence and homicide, cont'd

- Among certain types of homicides, individuals with severe psychiatric disorders are responsible for a much higher percentage:
 - Rampage murders: 42% had previously been psychiatrically evaluated, 20% had been psychiatrically hospitalized
 - Parents killed by children: 75% were severely mentally ill
 - Children killed by parents: 75% had had prior psychiatric care

Violence and homicide, cont'd

The Andrea Yates syndrome

- When Andrea Yates went to prison in 2002, she joined 69 other women who were in the Texas prison system because they had killed their children.

Violence and homicide, cont'd

The Andrea Yates syndrome

- When Andrea Yates went to prison in 2002, she joined 69 other women who were in the Texas prison system because they had killed their children.
- In 2003 in Texas, within 9 months, there were 4 additional killings of children by severely mentally ill parents who were not being treated.

Violence and homicide, cont'd

- Stigma: Homicides by individuals with severe psychiatric disorders are the single biggest cause of stigma. The most effective way to combat stigma is to make sure people are getting treated.

Violence and homicide, cont'd

- Stigma: Homicides by individuals with severe psychiatric disorders are the single biggest cause of stigma. The most effective way to combat stigma is to make sure people are getting treated.
- NAMI needs to speak out on the issue of violence. Don Richardson, President of NAMI 1986–87, stated it as follows:

“To say the mentally ill are no more dangerous than the general population is a statement all of us family members have been parroting for years because we try hard to break the stigma. ... In our intensity to reduce stigma NAMI is also losing a lot of credibility....”

“... Out of the mentally ill population, there is no question that there is a segment that is much more violent and to deny that is just reducing the credibility of our movement.... I believe it is time for NAMI members to come all the way out of the closet.”

Click [HERE](#) for additional data

III. How Can the Problem Be Fixed?

- Recognize the importance of anosognosia.

Anosognosia, cont'd

- There is a subgroup of individuals with severe psychiatric disorders who are not aware they are mentally ill and who will never take medication voluntarily.

Anosognosia, cont'd

- There is a subgroup of individuals with severe psychiatric disorders who are not aware they are mentally ill and who will never take medication voluntarily.
- These individuals are disproportionately found among those who relapse, commit suicide, are victimized, become homeless, are in jails and prisons, and commit violent acts.

Anosognosia, cont'd

- Pretending that such individuals do not exist is not a solution. They do exist, and until we recognize their existence, we will continue to have the problems described.

Click [HERE](#) for additional data

III. How Can the Problem Be Fixed?

- Recognize the importance of anosognosia.
- Identify the 10% of individuals with severe psychiatric disorders who are most at risk for causing problems.

Identify the 10%, cont'd

- A small subgroup of individuals with severe psychiatric disorders cause most of the problems. It is usually the same group of individuals who end up homeless, victimized, jailed, and violent. Although there is no good study, a reasonable estimate is that they constitute approximately 10% of all individuals with severe psychiatric disorders.

Identify the 10%, cont'd

- This group also accounts for a disproportionate share of expenses for the mental health system. A study in England reported that the 10% most severely affected patients account for 80% of the total costs.

Identify the 10%, cont'd

- It is possible to identify this 10% problematic subgroup. The most important predictors are:
 - History of past violence

Identify the 10%, cont'd

- It is possible to identify this 10% problematic subgroup. The most important predictors are:
 - History of past violence
 - Substance abuse

Identify the 10%, cont'd

- It is possible to identify this 10% problematic subgroup. The most important predictors are:
 - History of past violence
 - Substance abuse
 - Anosognosia with past nonadherence to medication

Identify the 10%, cont'd

- It is possible to identify this 10% problematic subgroup. The most important predictors are:
 - History of past violence
 - Substance abuse
 - Anosognosia with past nonadherence to medication
 - Antisocial personality disorder traits

III. How Can the Problem Be Fixed?

- Recognize the importance of anosognosia.
- Identify the 10% of individuals with severe psychiatric disorders who are most at risk for causing problems.
- Use leverage to ensure medication adherence.

Use leverage, cont'd

- Representative payee
- Access to housing
- Mental health courts
- Conditional release and Psychiatric Security Review Board
- Assisted outpatient treatment (outpatient commitment)

Effectiveness of Assisted Outpatient Treatment

1. Decrease in days hospitalized per year

	Prior to being on AOT	On AOT	Decrease
District of Columbia	55	38	-31%
North Carolina	22	14	-36%
Ohio	133	44	-67%
Iowa	33	5	-85%
New York	100	44	-66%
North Carolina	33	5	-85%

Effectiveness of Assisted Outpatient Treatment

2. Decrease in homelessness: 19% to 5% (NY)

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3. Decrease in victimization: 42% to 24% (NC)

Effectiveness of Assisted Outpatient Treatment

2. Decrease in homelessness: 19% to 5% (NY)

3. Decrease in victimization: 42% to 24% (NC)

4. Decrease in arrests: 45% to 12% (NC)
30% to 5% (NY)

Effectiveness of Assisted Outpatient Treatment

2. Decrease in homelessness: 19% to 5% (NY)

3. Decrease in victimization: 42% to 24% (NC)

4. Decrease in arrests: 45% to 12% (NC)
30% to 5% (NY)

5. Decrease in violent behavior: 42% to 27% (NC)
15% to 8% (NY)

Click [HERE](#) for additional data

Use leverage, cont'd

Methods for guaranteeing that individuals take medication

- Directly observed therapy (DOT)
- Long-acting injection
- Implantable medication devices
- Assays of blood or urine

It is essential that states with overly restrictive laws amend their laws to permit court-ordered treatment on an inpatient or outpatient basis without requiring proof of imminent dangerousness. . . . The laws in many states frequently function as impediments to treatment when people need it the most but may be too ill to recognize their own need."

Michael Fitzpatrick, 2007
NAMI Executive Director

The opposition to involuntary committal and treatment betrays a profound misunderstanding of the principle of civil liberties. Medication can free victims from their illness—free them from the Bastille of their psychoses—and restore their dignity, their free will and the meaningful exercise of their liberties.

Herschel Hardin, 1993

Use leverage, cont'd

What Is Needed in Addition to Medication

- Decent housing
- Fountain House—style clubhouses
- Rehabilitation programs
- Employment programs

III. How Can the Problem Be Fixed?

- Recognize the importance of anosognosia.
- Identify the 10% of individuals with severe psychiatric disorders who are most at risk for causing problems.
- Use leverage to ensure medication adherence.
- Fix state laws.

Fix state laws, cont'd

- Make assisted outpatient treatment available in all states. The following states do not now have it:

Maine
Massachusetts
Connecticut
New Jersey
Maryland
Tennessee
New Mexico
Nevada

Fix state laws, cont'd

- Change existing laws in the following states to make them more useful:

Missouri
Pennsylvania
Virginia
Washington

Fix state laws, cont'd

- Make greater use of the laws that are on the books but grossly underused, especially in the following states:

California
Florida
Indiana
Michigan
Minnesota
Texas
West Virginia

Fix state laws, cont'd

- Use the model outpatient commitment law prepared by the Treatment Advocacy Center.

Click [HERE](#) to see the law

Fix state laws, cont'd

- Use the model outpatient commitment law prepared by the Treatment Advocacy Center.

Click [HERE](#) to see the law

- Review the state laws in your state.

Click [HERE](#)

III. How Can the Problem Be Fixed?

- Recognize the importance of anosognosia.
- Identify the 10% of individuals with severe psychiatric disorders who are most at risk for causing problems.
- Use leverage to ensure medication adherence.
- Fix the state laws.
- Make information available to those who need to know.

Make information available, cont'd

- The use, and frequent misuse, of laws on confidentiality contribute to the failure to treat individuals with severe psychiatric disorders.

Make information available, cont'd

- The use, and frequent misuse, of laws on confidentiality contribute to the failure to treat individuals with severe psychiatric disorders.
- A list of individuals who have a past history of violence and have been court-ordered to stay on medication should be available to emergency room physicians and police officials. This could be maintained on a password-protected website.

Make information available, cont'd

- Court orders to take medication should be applicable across state lines. The problem is similar to that for individuals with active tuberculosis or vehicle drivers with epilepsy who may be a danger to other people if they do not take their medication regularly.

It must be remembered that for the person with severe mental illness who has no treatment, the most dreaded of confinements can be the imprisonment inflicted by his own mind, which shuts reality out and subjects him to the torment of voices and images beyond our powers to describe.

Supreme Court Justice
Anthony Kennedy, 1999

The paramount
civil right of the
patient should be
that of adequate
treatment.

Stephen Rachlin, 1974

This talk is available
online at:

[www.treatmentadvocacycenter.org/
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with links to pertinent
studies.