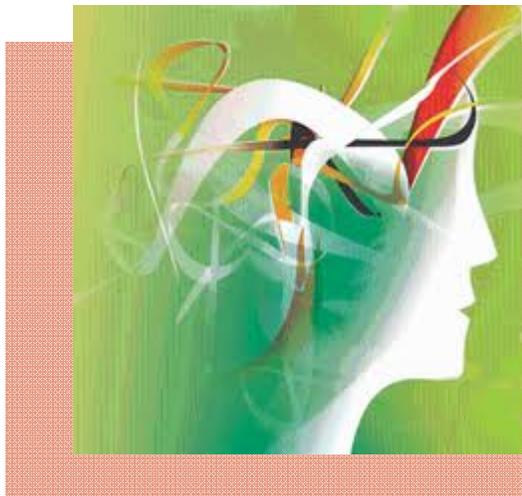

LPS REFORM
TASK
FORCE II



**The Case
For Updating
California's
Mental Health
Treatment Law**

MARCH 2012

SEPARATE AND NOT EQUAL

THE CASE FOR
UPDATING CALIFORNIA'S
MENTAL HEALTH
TREATMENT LAW

A Report of the LPS Reform Task Force II

Editors

Mark Gale

Randall Hagar

Carla Jacobs

Sheree Kruckenberg

Darby Patterson

Vincent Wales

Published by: The LPS Reform Task Force II

February 2012

POB 17602 17th Street, #102

Tustin, CA 92780

714-771-2321

We are grateful to the following people for their input and contributions to this report. Each brought a unique perspective and expertise to the process. Some were consulted others participated more actively in the work of committees. The Task Force operated by consensus, yet acknowledged differences in viewpoint among its members. Each member acted as an individual rather than a representative of the organization(s)/agency with which they are associated.

Gil Abdalian	Elizabeth Galton, MD	Paul Rains, RN, MSN
William Arroyo, MD	Randall Hagar	Jody Rawles, MD
Lauren Ball, LCSW	Steve Hawkins	Mary Read, MD
Ofc. Randy Beckx	Karen Henry, JD	Stephen Read, MD
Neisha Becton, Ph.D.	Robert Horst, MD	Joyce Riley
Theresa Berkin	Carla Jacobs	John Rouse, MD
Christina Bivona-Tellez BSN, MPH	Brenda Jensen, MD	Rod Shaner, MD
Andrew Booty, MD	Reza Karkia, DBA	Donald Sharps, MD
Stuart Buttlair, Ph.D, MBA	Judge Suzanne Kingsbury	Judge Maria E. Stratton
Jason Bynum, MD	Sheree Kruckenberg, MPA	Cass Sylvia
William Callahan MD	Kathleen Connolly Lacey, LCSW	Stewart Teal, MD
Gary Chang, JD	Richard Lamb, MD	Cap Thomson, MD
Elaine F. Crisostomo	Paul Linde, MD	Gary Tsai, MD
Paul Cumming	Judge Wendy Lindley	Vincent M. Wales
Steve Cummings, MD	Steve Lipton, JD	Robert Weinstock, MD
Jana Du Bois, JD, RN	Lucille Lyon	Nick & Amanda Wilcox
Robert Ervais, JD	Frank Maas, RN, BSN, MBA	Glen L. Xiong, MD
Ross Estrada	Judge Stephen Manley	Judith Yates, MPH, BSN
Ofc. Joel Fay, PsyD	Susan Masarweh, JD	Melinda Young, MD
Nancy Fernandez	Catherine Osborn O'Reilly, RN, MSN, BC	Denis Zilaff, JD
Mark Gale	Sgt. Barry Perrou, Psy.D (LASD, Ret.)	
	Cam Quanbeck, MD	

TABLE OF CONTENTS

INTRODUCTION	1
EXECUTIVE SUMMARY	3
RECOMMENDATIONS	8
SUMMARY & CONCLUSIONS	22
APPENDICES	25
Overview of Serious Mental Illness	25
Historical Background & Current State	33
Schizophrenia as Brain Disease	45

The LPS Reform Task Force---Who are we and what did we do?

Introduction

This report, the result of 30 months of study, seeks to generate reform of our adult mental health system in fundamental ways that include scientific knowledge with a renewed commitment to the underlying principles of the Lanterman Petris Short Act. Referred to as LPS, the Act is that portion of the California Welfare & Institutions Code (WIC) that governs involuntary civil commitment to psychiatric hospitals in California.

The Task Force consisted of individuals and organizations with first-hand experience and understanding of the complexities of California's current mental health treatment laws. Our study included a review and assessment of changes to the state's mental health system since the LPS Reform Task Force I issued its seminal report, *A New Vision for Mental Health Treatment Laws* in 1999.¹

Findings: Inpatient psychiatric beds have been substantially reduced² and emergency rooms are now at the forefront of battle^{3, 4} in mental health treatment. Parole realignment assumes that many individuals with mental illness will be treated in the community rather than prison, but little consideration has been given of the failure of the mental health system to prevent their initial incarceration.^{5, 6, 7} California's Assisted Outpatient Treatment statute, Laura's Law, was passed to reduce repeat hospitalization and jailing, but has only been implemented in two counties.⁸ The public adult system of care system received great influxes of additional funding most notably through the passage of Proposition 63, the Mental Health Services Act of 2004, but little of it has been directed to individuals who may need it involuntarily in the community or in a hospital.^{9, 10, 11} A person with severe mental illness is now four times more likely to be in jail than in a hospital beds.¹² The LPS Act is forty five years old and it has not changed in response to an evolving mental health delivery system.¹³

Questions:

What can be done legally and procedurally for people with mental illness who are:

- a) badly in need of treatment; b) likely to suffer significant harm without treatment; and,
- c) unlikely to accept and stay in treatment in the current system configuration?

Is the statutory involuntary treatment scheme being equally and consistently applied county-to-county and does it afford equal protection to the individuals who may be subject to it?

Introduction endnotes:

- ¹ <http://www.treatmentadvocacycenter.org/storage/documents/report%20by%20the%20lps%20reform%20ast%20force%20%20rdc%20pdf.pdf>
- ² <http://www.calhospital.org/general-information/psychiatric-inpatient-bed-data>
- ³ <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb92.pdf>
- ⁴ <http://articles.latimes.com/2011/jul/31/local/la-me-hospital-violence-20110731>
- ⁵ <http://www.cdcr.ca.gov/Parole/parole-realignment.html>
- ⁶ Markowitz FE: Psychiatric hospital capacity, homelessness and crime and arrest rates. *Criminology* 44:45-72,2006
- ⁷ Lam HR, WeinbergerLE, Marsh JS, et al, Treatment prospects for persons with severe mental illness in an urban county jail. *Psychiatr Serv* 58:782-6, 2007
- ⁸ http://en.wikipedia.org/wiki/Laura's_Law
- ⁹ <http://www.ebudget.ca.gov/2004>
- ¹⁰ <http://www.cccmha.org/announcements/govbudget>
- ¹¹ http://www.dmh.ca.gov/Laws_and_Regulations/docs/REGSDec29final.pdf
- ¹² <http://www.mentalhealthamerica.net/go/position-statements/52>
- ¹³ http://www.cdcr.ca.gov/comio/docs/MENTALLY_ILL_IN_JAILS_PAPER%20.pdf

Separate and Not Equal

How California's Mental Health System Discriminates Against People with the Most Severe Mental Illness

Executive Summary

Our state is at risk. Our once unchallenged preeminence in treatment and civil rights for individuals with mental illness has been tarnished as our treatment laws and mental health system have not kept pace with the complex needs of our most severely disabled individuals with mental illness.

Instead, certain names and events are etched into our collective memory: Aaron Bassler and the Fort Bragg killings; Kelly Thomas, beaten to death on Fullerton streets; and young Laura Wilcox murdered with two others at Nevada City's Behavioral Health Department.

Every tragedy seen in headlines is but a shadow of thousands more tragedies that go by quietly and unnoticed. Each is underscored by a common denominator: untreated severe mental illness.

Schizophrenia, clinical depression and bipolar disorder are brain disorders.* People with these severe mental illnesses come from all backgrounds and walks of life. Most recognize they have a mental illness and participate willingly in treatment. Many have a biologically determined inability to recognize, or consistently recognize, they are ill. Linked to frontal lobe dysfunction and brain abnormalities, they decline or fail to consistently engage in community mental health treatment. Instead, they revolve through short term hospitalizations, incarceration, homelessness, or—too frequently—tragic victimization, violence or death.

The LPS Act designed to govern involuntary civil commitment to psychiatric hospitals in California, reflects the then current political, legal and social ideas of the 1960s when it took effect in 1969.

Our society and its mental health treatment system seem to have lost sight of the basic purposes of the LPS Act and the high expectations and disciplined effort needed to attain them:

- To end inappropriate, indefinite, involuntary commitment
- To provide prompt evaluation and treatment

* For more information on brain disorders see Appendices starting on page 29, particularly the article by Cameron Quanbeck, MD.

- To safeguard individual rights
- To protect mentally ill individuals from criminal acts
- To guarantee and protect public interests

The LPS Act became the Magna Carta of civil rights for those individuals who are well enough to respond to treatment in a voluntary mental health treatment system. For others, the intervening 45 years since the passage of the LPS has represented increasing neglect and despair:

- Suicide: 15% of people with untreated or undertreated mental illness kill themselves.
- Homeless: 33% of homeless people have an untreated mental illness.
- Arrest: 20% of incarcerated inmates in both jails and prisons have a mental illness.
- Victimization: People with a mental illness are at least three times as likely to be assaulted or raped compared to the general population.
- Violence: 10% of all homicides are committed by individuals with a mental illness.
- Death: People with a mental illness die 25 years earlier than the general population.

Statistics show only the surface of the difficulties we face. Beneath lies a tension between hope, frustration and reality. But, the depth of reality is apparent.

- ✓ Being in the community has not been a solution for all people with severe mental illnesses.
- ✓ Involuntary treatment and coercion have increased through criminalization.
- ✓ Piecemeal legislative revisions of due process within the LPS Act may have had an unintended consequence of preventing quick and effective access to treatment or release.
- ✓ The incarceration of mentally ill individuals has risen dramatically since state hospitals starting releasing individuals to the community.

Prompt treatment and equal protection sometimes requires tough decisions. What is needed is reform that assures that the most severely disabled among us receive treatment in a system that recognizes the reality of mental illness and the scientific knowledge behind it.

Clearly, it's time. We can no longer tolerate neglect.

Summary of Recommendations

Following is a brief summary of recommendations contained in this report. Discussion is included in associated Problem Statements and Recommendations in the following sections of this report.

Recommendation #1: Define “Grave Disability” to address the individuals’ capacity to make informed consent to treatment and assess their ability to care for their health and safety.

Recommendation #2: Adopt concurrent legal processes to determine probable cause for hospitalization and capacity to refuse medication in one hearing.

Recommendation #3: Conform initial acute care hospital certification periods to 28 days, renewable for 28 days. Consider less restrictive alternatives to hospitalization at each hearing or upon renewal of holds.

Recommendation #4: Establish criteria for an LPS conservatorship to be “grave disability” as defined under Recommendation # 1 of this report. Establish conservatorships by clear and convincing evidence. Revise procedures to allow for efficient application and due process for conservatorships applied for from community settings.

Recommendation #5: Authorize an additional 90 day certification to continue acute care hospitalization for individuals who meet the demonstrated dangerousness standard in WIC 5300, with a right of appeal. Provide notice of application for impending post certification commitment under WIC 5300 to County District Attorneys and Public Defenders 30 days before expiration of the 90 day certification. Commitment should be for one year, renewable, with the relevant historical course of the individual’s illness considered during the trial, and demonstrated danger established by clear and convincing evidence.

Recommendation #6: Adopt a statewide standardized form to record the historical course of a person’s illness.

Recommendation #7: Develop local systems of interagency coordination to ensure timely transportation and placement in facilities appropriate to the person’s needed level of care.

Recommendation #8: Ensure Medi-Cal definitions for voluntary and involuntary hospitalization are consistently defined, monitored and applied. Appeals should be conducted by a neutral third party.

Recommendation #9: Prioritize services to the most seriously disabled adults with a mental illness whether those services are needed on a voluntary or involuntary basis in the community or a hospital setting.

Recommendation #10: Implement Assisted Outpatient Treatment (Laura's Law) statewide.

Recommendation #11: Expand mental health courts in all jurisdictions and increase the capacity and utilization of current mental health calendars statewide.

Recommendation #12: Conform local emergency response capability in each county under a legislative framework that requires standardized training for all designated response entities.

Recommendation #13: Set uniform state custodial standards for who can generate a 5150 hold and clarify who can enforce, release or continue that hold.

Recommendation #14: Ensure statewide uniform application of the Lanterman Petris Short Act to achieve equity and equal protection for all consumers statewide.

LPS and Recovery

Since the passage of the Mental Health Services Act in 2004, California has sought to increase the services delivered by the voluntary community-based mental health system. It has been a positive development that helped many engage in treatment and provided a wide array of community supports necessary for full recovery and a return to a productive life. Yet tens of thousands of other individuals with serious mental illness are unable to engage in their mental health treatment within that structure. This document seeks to provide recommendations that will provide assistance to these individuals with serious mental illness who are coming to harm in our communities, are revolving through our criminal justice system, are homeless, receiving only short-term crisis care in emergency rooms or repeated hospitalizations in the few acute inpatient facilities that still remain.

The Task Force sought to develop recommendations that would balance the right to self-determination of one's treatment with the needs of those individuals who, without some level of intervention and/or substitute decision making, might never have the chance to become healthy and join others who have chosen to embrace their personal journey of recovery. The "politics of recovery" in California surrounding these two groups of mental health consumers (those who accept treatment voluntarily and those who do not) has become divisive instead of inclusive. Appropriate emergency, short and long-term care provided with all due process considerations that facilitates treatment rather than acts as a barrier to treatment will serve to increase the numbers of persons willing to engage our voluntary mental health system enabling both levels of care to experience greater successful outcomes. The goal is to increase recovery for all. This cannot be accomplished by ignoring the challenges of a population of people with serious mental illness who are currently being treated in the least appropriate, most expensive and most restrictive settings such as jails, prisons, community hospital emergency departments and our state hospitals.

Although the passage of the LPS Act brought many needed reforms, the current statutory and procedural structure has been given its opportunity to show proven results for *all* and it has failed. With the appropriate and necessary reforms recommended by this Task Force, California can begin to move forward in providing desperately needed treatment and services to *all* its citizens with serious mental illness.

Conclusion

The Lanterman Petris Short Act was intended to protect persons with serious mental illness from inappropriate and indefinite institutionalization. The statute was not intended to act as a barrier to treatment, but rather to rapidly facilitate due process and appropriate treatment. It has succeeded in allowing the majority of Californians with mental illness to achieve self-determined recovery in the community. For others, however, it has led to isolation, discrimination, criminal institutionalization, abuse and neglect, deterioration in health and mental health, and a violation of their civil rights.

"I wanted the LPS Act to help the mentally ill. I never meant for it to prevent those who need care from getting it. The law has to be changed."

Frank Lanterman

RECOMMENDATIONS

A Note on the Recommendations: The mission of the Task Force was to increase access to treatment and early intervention at appropriate levels of care for people with severe mental illness who require involuntary intervention. Such care should be delivered in a manner that decreases discrimination, criminalization and homelessness while improving due process and the efficiency and coordination of the legal and service delivery systems in a cost-effective manner. The final recommendations below reflect that mission. Also, throughout this white paper the term “psychiatric treatment” may include necessary medications as well as community services and supports with a recovery orientation.

1. Criteria for Inpatient Evaluation & Treatment Problem Statement

A person may be involuntarily treated only if that person meets statutorily defined criteria. Current California law emphasizes deinstitutionalization of people from long-term, state-run, psychiatric hospital facilities. Today, as the original LPS proponents intended, state institutions are nearly a thing of the past. No one advocates a return to unnecessary long-term placement; our dilemma is how to provide treatment to people who lack the capacity to make decisions about psychiatric treatment and to accept or access it themselves, and who live in a community environment.

To do this, the criteria in California’s 45-year old LPS Act must be updated to incorporate current medical science regarding mental illness. It should correspond more closely with the Medi-Cal definition of ‘medical necessity’ and, most importantly, provide treatment before tragic social, criminal justice and/or medical consequences occur. Further, the laws must help de-stigmatize mental illness by recognizing that individuals with mental illness deserve parity in treatment as provided to individuals with other judgment-impairing medical conditions when symptoms of a mental illness render them unable to accept, obtain or utilize such treatment for themselves.

RECOMMENDATION #1:

The “gravely disabled” standard specifies that an individual is incapable of satisfying his or her need for either nourishment, personal or medical care, shelter or self-protection.¹ This standard should be redefined to incorporate an added element that addresses the capacity of the person to provide informed medical decisions. The gravely disabled standard should also be amended to incorporate specific criteria that includes more comprehensive details such as the probability the person would experience substantial bodily harm, serious illness, significant psychiatric deterioration or debilitation without adequate treatment.

Furthermore, a standard of “incapable of making an informed medical decision” would offer practical guidance to help assure uniform statewide application of the statute, and should be included in any amended statute. An individual’s medical and psychiatric history should be considered when making a grave disability determination, as required by current law,² and a specific reference to that must be inserted in any new amendments to the grave disability statute.

2. Riese Hearing Problem Statement

California’s law currently divides the legal processes of commitment from the clinical processes of treatment. Derived from a court case of the same name, a Riese hearing determines a person’s capacity to give informed consent, in this case to accept or refuse psychotropic medication.³

Wide variation in procedure exists from county to county,⁴ with some counties holding Riese hearings simultaneously (or back-to-back) with Welfare and Institutions Code Section 5250 certification hearings, while others hold them as distinct hearings separate in time and place. In some cases, the interval between an initial detention for evaluation and the determination of capacity to make an informed decision regarding psychotropic medication can take seven days and is regularly longer. Having an interval of this length produces an inherently cruel and costly circumstance forcing medical professionals to confine a psychotic, delusional, suicidal or dangerous patient to an inpatient unit without being able to provide necessary treatment, including needed medication.

¹ California Welfare and Institutions Code Section 5332 et. seq. (WIC §5332) / ²WIC §5008.2 / ³Riese v. St. Mary’s Hospital & Medical Center, 209 Cal.App3d 1303 / ⁴Survey, LPS Reform Task Force II of County Counsels

Additionally, the Riese hearing statute restricts consideration of capacity to make informed consent to a person who is actively refusing psychotropic medication, while there is no statutory requirement to examine the capacity of individuals who accept medication. Some individuals simply take medication because it is given to them. Individuals who accept medications, yet who lack capacity to make informed decisions regarding psychotropic medications, may therefore be denied the right and benefit of a substitute decision maker or decision-making process to protect them from potential abuse from inappropriately prescribed medication.

RECOMMENDATION #2:

Adopt concurrent legal processes to determine probable cause for hospitalization and capacity to refuse medication in one hearing. During the initial 72-hour period for evaluation and treatment, the treating physician should be required to evaluate whether or not the patient who is refusing clinically appropriate and medically indicated medication has the medical capacity to do so. If the patient has previously signed an Advance Directive assigning substitute decision-making for treatment to a professional or family member in the event that his or her judgment becomes impaired, and a copy of that Directive has been provided to the treatment facility, medication will be administered only under the terms of the Directive unless the person is imminently dangerous to self or others.

If the person has not assigned a substitute decision-maker and in the treating physician's opinion the patient does not have the capacity to make medication decisions, the patient would benefit from medication and would most likely deteriorate further without medication. A Riese hearing should be initiated so that medication may be administered even over objection. Before any administration of medication, the treating clinician must make reasonable attempts to obtain the patient's agreement. Treating staff should be sensitive to all input given by the patient or his/her family regarding complaints of side effects, previous medications used or problems with the prescribed medication.

3. Length of Certification Problem Statement

Holds for involuntary psychiatric treatment vary according to the statute cited. For example, a WIC §5150 hold is generally 72 hours and a WIC §5250 hold adds an additional 14 days. There are other circumstances in which a hold may be extended, such as when a person is deemed “dangerous” to self or others. Counties in California use different approaches to determine which holds to place and therefore the length of time accumulative holds represent. Application deadlines imposed for the filing of temporary conservatorships also vary. Some counties use the 30-day LPS hold provision⁵ while some do not. Thus, depending on geographical location and varied timelines, individuals throughout California are being given widely divergent access to due process procedures as well as treatment.

One of the underlying assumptions in the LPS statute is that patients determined incompetent to provide informed consent are presumed to have regained competency when their hold status expires or changes. This may not be the case and the assumption can negatively affect the success and continuity of a patient’s treatment, sometimes delaying their recovery and release from an inpatient setting. These inconsistent practices also ignore the individual’s right to rapid access to treatment.

The process that currently exists under the LPS Act is often unnecessarily lengthy, multi-layered, non-therapeutic, cumbersome and costly. The California model is frequently referred to as the most complicated and “Byzantine” in the nation.

RECOMMENDATION #3: After the 72-hour period, certification for treatment should be for 28 days, regardless of the criteria under which the patient was initially certified, and renewable for an additional 28-day period. At each certification or renewal, consideration of conservatorship, Assisted Outpatient Treatment⁶ or extended order of medication in the community should be considered as less restrictive options.

⁵ WIC §5270.10

⁶ WIC §5345 et.seq.

4. Conservatorship Problem Statement

WIC §5350 of the LPS Act provides that a substitute decision maker with court granted powers may make treatment decisions for individuals who have been placed on a conservatorship due to grave disability, currently defined as the inability to effectively use food, shelter or clothing if provided to them. This conservatorship is not available to individuals who have been hospitalized under criteria of danger to self or others despite the fact that they may be in need of substitute decision making.

In an effort to remedy these inequalities, in some California counties, well-intended local clinicians and officials stretch the criteria for an LPS conservatorship from “dangerous to self or others” to a finding of “gravely disabled.” A simpler and more rational response would be to provide the LPS conservatorship option to any person with a mental illness who lacks the capacity to provide informed medical decisions regarding their treatment needs. In making the consideration of whether the person fits the criteria for a conservatorship, the courts should also take into account the historical course of a mental illness in addition to the individual’s presenting mental condition.

Moreover, while the LPS Act allows for application for a conservatorship from the community, the procedures to obtain one are so complex and convoluted that the legal provision is rarely, if ever, used. As a result, the vast majority of LPS conservatorships must be initiated from a hospital setting. Therefore, some individuals who lack capacity to make their own treatment decisions may be subjected to unnecessary inpatient hospitalization or receive no help at all.

California is one of the only states to require that a conservatorship can only be granted if determined under the “beyond a reasonable doubt” standard—a standard that is normally restricted to criminal cases. This requirement means that some people will be denied help because the bar was set—some would say arbitrarily—too high. A person who is incapacitated due to mental illness is not a criminal and should receive help and treatment without having to qualify under criminal standards.

RECOMMENDATION#4: LPS Conservatorships should be available for any person who lacks the capacity to make informed decisions regarding treatment and meets the standard of grave disability as proposed in Recommendation 1 of this report. Procedures within the LPS Act should also be revised to allow efficient application from a community setting to avoid unnecessary inpatient hospitalization when the community is the least restrictive environment appropriate for the person's needs. The standard for LPS Conservatorship should be clear and convincing evidence. A judicial order appointing a conservatorship should be recognized by officials in other California counties and apply throughout the state, rather than only in its county of origin.

5. Demonstrated Danger Problem Statement

The only true civil commitment in California occurs under WIC§5300, which allows a person who is a “demonstrated danger to others” to be placed on a 180-day commitment following an initial 14-day certification for involuntary treatment. This section of the LPS Act is rarely used. It stipulates that, prior to or during the initial hospitalization period, the person demonstrated a danger of inflicting substantial physical harm on others and that the demonstrated danger was based on “infliction, attempt or serious threat of harm.”

Danger of this level rarely occurs in a supervised hospital environment. Individuals who have been hospitalized due to danger to others, but who have not reached this higher standard of demonstrated danger, are simply released after a completion of the 14-day certification under WIC §5250. However, even for those few patients who, because of symptoms of their illness, have demonstrated inpatient danger, the procedures involved in obtaining a 180-day commitment are so stringent that they are often a barrier to needed treatment and supervision.

The person detained under WIC §5300 must be brought to trial within 10 days unless his or her public defender applies for an extension, is granted a jury trial (if so desired) and is found to be a demonstrated danger beyond a reasonable doubt. During the 180 days, which is renewable, the person may be placed in a locked psychiatric facility or placed

on outpatient committal status. The outpatient committal may happen only if the professional in charge of the facility and the county mental health director advise the court that the person will no longer be dangerous, will benefit from outpatient status and will participate in an appropriate program of supervision and treatment.

The limit of commitment (180 days) may not allow sufficient time for in-hospital stabilization as well as successful reintegration to the community through supervised outpatient committal. It's often the case that more treatment time is needed to reach stabilization and remove the threat of danger.

Additionally, the law currently provides that "demonstrated danger" may be based on assessment of present mental condition, which is based upon a consideration of past behavior of the person within six years prior to the existing incident. The six-year time frame is an arbitrary period, which will not necessarily contain essential historical course of illness information regarding the person's mental illness.

RECOMMENDATION #5: If the person has proven to be a demonstrated danger to others during the initial WIC §5250 certification, an additional certification period for 90 days of acute care hospitalization should be allowed. The patient should have the right to appeal this additional certification through a writ to the Superior Court. If, at the end of 60 days of the additional 90-day certification period, the person is thought to be a continuing demonstrated danger to others, notification should be given to the County District Attorneys office and Public Defenders office of the impending commitment application in order to allow adequate time to prepare for trial to determine commitment.

The finding for a commitment of demonstrated danger should be based on clear and convincing evidence. The length of the commitment should be extended from 180 days to one year to conform to the term of conservatorship in order to provide the individual sufficient time to gain treatment stability and community reintegration. Commitment should be renewable annually.

WIC §5300.5(c) should also be modified so that ‘demonstrated danger’ is based on assessment of present mental condition, with no time limitation regarding consideration of the individual’s past behavior. The historical course of the person’s mental disorder shall be considered when it has a direct bearing on the determination of whether the person is a danger to others under this code section.

6. Historical Course of Illness Problem Statement

AB 1424 (Thomson, 2002), which is existing state law,⁷ provides that the historical course of a person’s mental illness shall be considered in all involuntary commitment proceedings, from detention and transport in the community through the long-term care provisions in conservatorships. Although AB 1424 became law in California on January 1, 2002, information concerning the historical course of a person’s mental illness continues to be considered randomly both within and between California jurisdictions. There is little consistency in its application due to a lack of education regarding the requirements of the law and absence of a standardized and accepted process for implementation.

Recommendation #6: The historical course of an individual’s illness shall be considered at each step of the involuntary process. A standardized AB 1424 form should be developed and approved by the appropriate state mental health agency and other necessary governmental agencies as needed and used in every county of California. This standardized form should be accepted and used by every police force, sheriff’s department, psychiatric mobile response team, clinical/medical facility, superior court and hearing officer in California.

7. Non-designated Hospitals Discussion Problem Statement

Designated hospitals are facilities designated by a county and approved by the state for the evaluation and treatment of persons detained under the LPS Act.

Non-designated hospital emergency departments are not capable of offering the level of care and treatments required for most involuntarily detained mental health

⁷ WIC §5008.2

patients or even those who are admitted voluntarily. Substantial numbers of those persons being involuntarily evaluated under LPS regulations first arrive at non-LPS designated emergency departments. Multiple federal, state and local regulations come into conflict with one another as non-LPS designated emergency departments attempt to properly care for and place mental health patients in appropriate psychiatric beds.

RECOMMENDATION #7: The State shall develop a system of interagency collaboration among mental health departments, law enforcement, designated and non-designated hospitals and transport entities. This should be done under a legislative framework that requires a specific administrative entity to be responsible for oversight, coordination, interagency payment and accountability. This framework would ensure rapid placement in and access to a facility appropriate to the person's needed level of care, as well as providing standardized training to all public and private entities designated to make such a placement. Compliance standards for both voluntary and involuntary hospitalization should be uniformly implemented and monitored statewide.

8. Medical Necessity Problem Statement

"Medical Necessity" definitions in Medi-Cal statutes and regulations for both voluntary and involuntary hospitalizations are not clinically appropriate for acute psychiatric episodes and are not being defined, monitored or applied consistently throughout the state. The appeals process for a denial of payment is heard by the same entity that "pays the bill"— the local mental health plan— and usually occurs retroactively after the patient's discharge. Thus, financial incentives exist for both mental health plans and providers to prematurely discharge psychiatric patients, which can increase the likelihood of negative outcomes.

RECOMMENDATION # 8: Adopt medical necessity definitions appropriate to acute psychiatric illness episodes and ensure that Medi-Cal definitions for both voluntary and involuntary hospitalization are consistently defined, monitored and applied with appeals to be conducted by a neutral third party.

9. Hospital Bed Reduction Problem Statement

Over the past two decades, the number of acute psychiatric inpatient beds has decreased 30% throughout California. Twenty-five of California's 58 counties have no adult inpatient psychiatric beds. Based on population, California has one psychiatric care bed for every 5651 residents; nationwide, the average number of acute care psychiatric beds is one for every 4887 people.⁸ California's community mental health system has not been able to compensate for the loss of these beds. Many people with severe mental illnesses are just too ill to be treated in a voluntary community setting and the vast majority of community mental health services are not geared to those individuals' clinical needs. Also, treatment needs have become more complicated with an increased number of those with severe mental illnesses having co-occurring medical conditions such as addictions or chronic physical health conditions coupled with a mental illness.

RECOMMENDATION #9: The recognition that some people, due to the severity of their illnesses, will experience acute episodes that require inpatient treatment must be acknowledged and corresponding policy incorporated into all aspects of the adult mental health system of care. Crisis stabilization services should be available in every county and a full array of step-down levels of care should be available to increase opportunity for recovery. Priority should be given to the most seriously mentally disabled adults, whether services are needed by them on an involuntary or voluntary basis in the community or in a hospital setting.

10. Assisted Outpatient Treatment Problem Statement

Laura's Law is "on the books."⁹ However, implementation in any particular county requires a public hearing process that is so complex and cumbersome that few county boards of supervisors are willing to take on the commitment. Along with the lengthy and contentious hearing process, County mental health directors must prove that implementation of the law will not reduce voluntary services and, further, county supervisors must pass a resolution verifying that there will be no reduction in voluntary

⁸ <http://www.calhospital.org/general-information/psychiatric-inpatient-bed-data>

⁹ WIC §5345 et.seq.

services. Because of these significant complexities, Laura's Law has been implemented in only two of the state's 58 counties.

Lack of implementation of Laura's Law deprives communities of an effective early intervention tool that can prevent costly, potentially dangerous deterioration when an individual is refusing treatment. This tool could be one of many that could help people with histories of repeat hospitalization or arrest due to threat of violence. Laura's Law targets a small but significant population that poses the greatest risk to public safety. Implementation would have clear benefit for courts, law enforcement and emergency responders, as well as hospital emergency departments. At the same time, individuals with a severe mental illness will receive needed treatment before a public tragedy occurred.

RECOMMENDATION #10: More fully implement Laura's Law statewide. Remove the requirement of a Board of Supervisors resolution in order to make Laura's Law more available statewide. Review and develop an expansion strategy based on the report to the Legislature required on July 31, 2011. Extend or remove the current sunset date of January 1, 2013.

11. Mental Health Courts Problem Statement

The California Department of Corrections and Rehabilitation (CDCR) reported that one in seven parolees were enrolled in mental health programs while incarcerated. Recidivism rates for these parolees were higher than for any other subset of parolees, with more than three out of four re-offending and being sent back to prison. Under California's 2011 Public Safety Realignment, new protocols have been established for Post Release Community Supervision (PRCS) for non-serious, non-violent, non-sexual offenders. These probationers will not be returned to prison for violations, but serve their sentences in the county jail and then remain in the community with the need for forensic specialized mental health services and supports.

Since the LPS Act was passed in 1967, two generations of people living with the symptoms of serious mental illness have been criminalized. In fact, the population of persons who fail to engage in the community mental health system has been trans-institutionalized from state hospitals and acute inpatient facilities to our jails and prisons. Although well-intentioned when developed, the reliance on the existing criteria as written in the Lanterman Petris Short Act has set a standard that left California with the unintended consequence of criminalizing many thousands of individuals over the last forty years. Yet, with balanced and substantive reforms, those requiring assistance might have the opportunity to get the treatment and support they need before they commit a criminal offense .

Finally, all California counties have dramatically reduced mental health programs over the last four years in response to the ongoing economic crisis. There is a growing body of evidence that shows significantly increased incidents of police interdiction of persons with serious mental illness in the community with the resulting increase in court appearances as programs are cut or consolidated.

RECOMMENDATION #11: Seek expansion of mental health courts and mental health calendars in all jurisdictions and increase the capacity and utilization of current mental health courts.

12. Emergency Response Problem Statement

Emergency response to mental health crisis varies throughout the state. Some counties have mobile psychiatric response teams; others may rely heavily on private versions of these teams, while most counties have none at all. In many cases, law enforcement, fire departments and emergency medical services (ambulances) are the only available response when individuals are in a psychiatric crisis due to mental illness. Yet, first responders may not be able to appropriately intervene if they are

not aware of community mental health resources or alternatives to hospitalization. First responders may not have the authority to detain individuals under the LPS Act, may not have information regarding which hospitals are LPS-designated and/or may lack sufficient training to determine what components of the emergency situation may be related to mental illness.

Several jurisdictions in California have developed successful law enforcement/mental health collaborations to ensure that an appropriate response occurs when people are in crisis because of a mental illness and require emergency services. The best practices of these collaborative working relationships must be replicated and expanded to fire departments, other law enforcement agencies and emergency medical services.

RECOMMENDATION #12: Each county shall develop a comprehensive and coordinated emergency response capability under a legislative framework that requires emergency responder and mental health interagency collaboration and standardized training for response teams.

13. Non-Designated Hospitals Problem Statement

There is considerable variation in opinion as to peace officer obligation to remain present and retain custody for the duration of an individual's stay at a non-designated facility while on a 5150 hold. Non-designated hospitals are often recipients because they are closer to the transporting authority or because there are acute physical health conditions which need immediate emergency attention. There are very few designated facilities when compared to non-designated facilities in California communities. In addition, there is some difference of opinion as to whether the 5150 hold remains in force and effect if a custodial officer is not present. There is also ambiguity as to whether or not the initiation of a 24-hour hold by an emergency department¹⁰ dissolves the 5150 hold of the custodial officer.

¹⁰ Health & Safety Code Section 1799.11 (H&SC §1799.11)

If the transporting officer departs, emergency departments of non-designated hospitals often place a 24-hour emergency room hold on the individual to resolve the uncertainty, even if a 5150 hold is preferred or more appropriate for its longer duration. For example, an emergency room physician may determine that an individual who may be experiencing an acute episode of mental illness also needs to detoxify from intoxicating substances or, if there is a physical injury or a medical condition, those issues must be stabilized and medically cleared before psychiatric treatment can be addressed.

These issues raise the question of the ability of an emergency physician in a non-designated facility to enforce the 5150 hold until the patient in his care can be transferred to a designated facility. In addition, physicians may face a liability risk by ordering an unauthorized detention.

Police officers may leave non-designated hospitals without turning over documentation indicating that they have detained and transported an individual under authority of a 5150. When police officers do provide documentation to the hospital, it is unclear as to whether or not it imposes a legal obligation on a non-designated hospital.

If an individual is medically cleared and the emergency department arranges transportation to a designated facility for a psychiatric assessment, ambulance companies designated for transport may not recognize a 5150 without any documentation or may reject the documentation as not legally binding and refuse to accept perceived liability in transporting the individual.

RECOMMENDATION # 13: There should be a uniform state standard of custodial requirements for personnel who generate a 5150 hold and greater specificity in the LPS Act regarding status of detention, who can continue a hold, who can enforce a hold and who can release a hold. A workgroup consisting of representatives of hospitals, county counsel, law enforcement and transportation entities should be established to produce a uniform standard that can be incorporated into statute.

14. Cross-Cutting Issues Problem Statement

California is not only a huge state but a diverse state with a number of large urban areas and many rural or small county areas. California's realigned mental health delivery system is also a decentralized system in which county mental health systems, and not the state, deliver the majority of mental health services in the local community and in which funding and administrative authority for mental health programs are vested in counties. This arrangement of minimized state involvement provides flexibility in California's many diverse regions to tailor programs to local needs. This in turn has also led to wide variability in ways of doing business from county to county, in the availability of particular mental health services, in local policies and priorities, as well as application of the laws governing community mental health services.

Uniform application of the Lanterman Petris Short Act is lacking on a county-to-county basis.¹¹ This poses a number of dilemmas and raises issues of equity and equal protection. For instance, a determination of a person as gravely disabled in one county does not necessarily mean that the same person in the same circumstances would be determined to be gravely disabled in another county. So, too, coordination across county lines over issues governed by the Lanterman Petris Short Act is difficult and in some cases impossible. For instance, the authority of the Public Guardian often ends at the county line so that other counties may not recognize or acknowledge the powers of conservatorship within their own jurisdiction.

State guidance and oversight over LPS issues is often lacking or non-existent. For instance, involuntary medication due process procedures (called Riese hearings) are conducted in a bewildering variety of ways in a variety of settings. No state guidance has been issued on this subject. In particular, no regulations exist that would help achieve uniform interpretation of the applicable statute. In response, the Superior Courts in four counties (Kern, Los Angeles, San Diego, Tulare) have produced local rules of court to govern intra-county consistency in the Riese hearing process while the remaining 54 have no such formal guidance.¹²

¹¹ Lanterman Petris Short Act (LPS) Dialogue Project summary report (Department of Mental Health, 2002) / ¹² LPS Task Force Survey, 2009, accessing www.courtinfo.ca.gov/rules/localrules

Similar issues and concerns arise in transporting individuals:

- Between hospitals and across county lines
- Sharing psychiatric records concerning individuals between counties
- Records shared between state institutions and counties
- Between hospitals and county mental health authorities
- Between those authorities and hospitals or emergency rooms

RECOMMENDATION #14: Ensure statewide uniform application of the Lanterman Petris Short Act to achieve equity and equal protection for all consumers statewide.

SUMMARY & CONCLUSIONS

To better serve the course of justice, civil rights and the people of California, it is critical that the LPS Act be updated. Not only should it embrace new scientific findings about mental illnesses, it should better reflect the intentions of the 1967 legislation to create equity and parity for all the state's residents. As part of this mission, Laura's Law must be implemented in counties throughout the state. Applying only to a very small minority of people whose mental illness is so severe it poses a danger to the public and to themselves, Laura's Law will help to prevent public tragedies that lead to unnecessary violence and deaths.

The passage of time has revealed both strengths and weaknesses in the LPS Act. This set of carefully considered recommendations offers specific changes that will improve the delivery of justice and mental health treatment under the LPS Act. In addition, advances in medical science over the past four decades provide new understanding and options for the treatment of mental illness. Using these resources, the experience over time and advanced scientific knowledge, we have an opportunity to build a more just and equitable California for all our people.

“There is a sizable minority of persons with serious mental illness who do not believe that they are mentally ill and, as a result, are generally resistant to psychiatric treatment (including medications).”

Dick Lamb

“... the Riese case cloaked anti-treatment ideology in the language of civil rights ...”

Jonathan Stanley, JD

“My sister did not meet the criteria for involuntary treatment even though she was living on the streets with her 10 year old son. She became a criminal and qualified for treatment simultaneously when she murdered our 78 year old mother. Waiting for danger is too late.”

Brian Jacobs

“The longer an incompetent patient may lawfully reject antipsychotic medication which, in the judgment of medical professionals, may offer therapeutic benefit, the more tenuous the possibility for effective crisis management.”

Justice Benson,
Concurring in the opinion of Riese v St. Mary's (209 C.A.3d 1303)

APPENDICES

Acknowledgments: We want to gratefully acknowledge the contributions of many individuals in helping to collect the information contained in these appendices. Special thanks are owed to the Treatment Advocacy Center¹³ for generously making available many of their excellent fact sheets, from which much of the following material is derived.

I. Overview of serious mental illness: Schizophrenia and bipolar disorder

Cameron Quanbeck, MD

Schizophrenia is a condition that first shows clear manifestations in males in adolescence and in females in early adulthood. Bipolar disorder typically develops in both genders in the early to mid 20s. Both disorders are biologically-based and have a strong genetic component, e.g. they are passed down in families.

Approximately 2% of the population, 1 in 50 persons, suffers from these serious mental illnesses. Both illnesses, if left untreated, exhibit a remitting-relapsing or fluctuating course. Adverse events (hospitalization, arrest, jailing, and violent behavior) are most likely to occur in the manic phase of bipolar disorder and during relapses into psychosis in schizophrenia.

In recent years, a large amount of research has clearly demonstrated that a significant percentage of patients (40-50%) with serious mental illnesses suffer from deficits in insight. Those with impairments in insight are unable to or have difficulty realizing: 1) they are suffering from a serious mental illness; 2) the symptoms they experience, e.g., delusions, hallucinations, mania are part of the mental illness; and, 3) that they would benefit from psychiatric treatment. (Cairns et al., 2005; Dell'Osso et al., 2002; Pini, Cassano, Dell'Osso, & Amador, 2001; Pini et al., 2003). This difficulty accepting one's mental illnesses is biologically-based; those with a serious mental illness who lack insight into their illness have abnormalities in the parietal and temporal lobes of the brain when compared to those who retain insight (Cooke et al., 2008).

¹³ www.treatmentadvocacycenter.org

Persons with a serious mental illness who have impaired insight and ability to make treatment decisions are more likely:

- To receive involuntary rather than voluntary psychiatric treatment
- Fail to take their prescribed medication in the community and function poorly (Mohamed et al., 2009; Olfson, Marcus, Wilk, & West, 2006; Yen et al., 2005)
- To experience more hospitalizations, suicidal and violent behavior (Yen, Chen, Yen, & Ko, 2008)
- To be more socially dysfunctional (Lysaker, Bell, Bryson, & Kaplan, 1998)

Insight can improve with treatment. If patients with poor insight who initially resist taking medication are ordered to take medication, after a month of treatment, the vast majority of patients (83%) retrospectively agreed with the decision to order medication against their wishes, e.g. they regained insight into the benefits of treatment (Owen et al., 2009). Patients who have frequent mood episodes also lose insight (Yen, Chen, Ko, Yen, & Huang, 2007). From a population perspective, 1% of California's population has both a serious mental illness and also suffers significant impairments in insight, which is about 370,000 of its citizens.

2. Adverse consequences of untreated mental illness

Persons with a serious mental illness who do not engage in psychiatric treatment suffer a multitude of adverse consequences that make addressing this issue a high priority. Some of the devastating consequences for the patient themselves include:

Neurotoxicity:

Neuroimaging studies have demonstrated that episodes of psychosis in schizophrenia and mood episodes in bipolar disorder damage critical brain regions, including:

- The prefrontal cortex (McClure et al., 2006; Moore et al., 2009)
- The cingulate gyrus (Atmaca, Ozdemir et al., 2007; Sassi et al., 2004)
- Hippocampus (Atmaca, Yildirim, Ozdemir, Ogur, & Tezcan, 2007)

Conversely, studies have demonstrated that taking psychotropic medications protects the brain against this damage (Stip et al., 2009).

3. Consequences of delaying treatment in persons with schizophrenia

Compared with those individual who are treated at the onset of schizophrenia, those with schizophrenia with a significant duration between onset and treatment experience:

- A poorer response to treatment and more severe and persistent symptoms (Gunduz-Bruce et al., 2005; Haas, Garratt, & Sweeney, 1998)
- Deficits in attention and memory and a lower verbal IQ and verbal learning ability (Atmaca, Ozdemir et al., 2007; Lappin et al., 2007)
- A higher likelihood of being unemployed, on disability, and cost three times as much to treat compared to those who receive early treatment (Mihalopoulos, Harris, Henry, Harrigan, & McGorry, 2009; Sarotar, Pesek, Agius, Pregelj, & Kocmur, 2008)
- Less likelihood of recovery from their illness (Mihalopoulos et al., 2009)

4. The high costs of acute psychiatric care

The most expensive form of mental health treatment is acute care provided in emergency rooms and psychiatric inpatient units. Patients with serious mental illness who do not take their prescribed medication in the community are at high risk of relapse and acute psychiatric care. Patients who relapse and are hospitalized also incur increased costs in the two months after hospital release (Fitzgerald et al., 2009). Even small decreases in medication non-adherence can lead to large financial savings for a health care system (Damen, Thuresson, Heeg, & Lothgren, 2008; Gianfrancesco, Sajatovic, Rajagopalan, & Wang, 2008). Failing to continue taking medication after release from the hospital dramatically increases risk of re-hospitalization (Hassan & Lage, 2009); even missing one prescription refill dramatically increases the risk of a psychiatric hospitalization for persons with schizophrenia (Law, Soumerai, Ross-Degnan, & Adams, 2008).

A study of California Medi-Cal recipients with schizophrenia found that those who were non-adherent to prescribed medication were twice as likely to be hospitalized than those who were adherent (Gilmer et al., 2004). Similarly, Californians with bipolar disorder in managed care plans who do not adhere to medications are twice as likely to use emergency and inpatient services (Lew, Chang, Rajagopalan, & Knoth, 2006). Those with serious mental illness who do not adhere to medications cost a health system three times

as much annually than those who take medications regularly (Knapp, King, Pugner, & Lapuerta, 2004). Risk of hospitalization was significantly correlated with compliance. Lower compliance, however defined, was associated with a greater risk of hospitalization over and above any other risk factors for hospitalization. For example, the presence of any gap in medication adherence was associated with increased risk of hospitalization. A gap as small as one to ten days produced an odds ratio [OR] of 1.98, or nearly twice the likelihood for hospitalization when compared to no gaps in medication. A gap of 11 to 30 days was associated with an OR of 2.81, and a gap of more than 30 days was associated with an OR of 3.96 (Weiden, Kozma, Grogg, & Locklear, 2004).

A study of Wisconsin Medicaid participants with schizophrenia found that irregular medication users had significantly higher rates of hospitalization than regular users (42 percent versus 20 percent), more hospital days (16 days versus four days), and higher hospital costs (\$3,992 versus \$1,048). Irregular medication use was one of the strongest predictors of hospital use and costs even after the analyses controlled for diagnosis, demographic characteristics, baseline functioning, and previous hospitalizations (Svarstad, Shireman, & Sweeney, 2001).

In the United States, there are roughly 87,000 annual acute care inpatient admissions of Medicaid patients for the treatment of schizophrenia. These admissions include a total of approximately 930,000 hospital days at a total cost of \$806 million. Improving adherence to eliminate gaps in antipsychotic medication treatment could lower the number of acute care admissions by approximately 12.3% and reduce the number of inpatient treatment days by approximately 13.1% resulting in a savings of approximately \$106 million in inpatient care costs for the national Medicaid system.

In short, poor adherence to antipsychotic medications was consistently associated with higher risk of relapse and rehospitalization and higher hospitalization costs. To reduce the rate of hospitalization and the cost of hospitalizations among patients with schizophrenia, it seems clear that efforts to increase medication adherence should be undertaken (Sun, Liu, Christensen, & Fu, 2007).

5. The financial consequences of arrest and incarceration

In 2009, California's prison population numbered 174,000 inmates, while California's jail population averaged 75,339. Data from the State of California indicates that about 32,000 prisoners during this period had a severe mental illness, while almost 200,000 individuals received psychiatric outpatient services in jails settings, which amounts to about 17,000 jail inmates with a severe mental illness at any one time. Another 25,000 parolees had severe and persistent mental illness. Clearly the amount of individuals receiving care in the criminal justice system is a significant portion of the population that qualifies for treatment in California's public mental health system.

According to Jean Fraser, Chief of the San Mateo Public Health System, the annual costs of providing mental health care in various settings varies widely, the most expensive of which is within the criminal justice system (see table below). Providing mental health care in the criminal justice system places a heavy financial burden on county and state government. The costs of housing and treating a mentally ill inmate in a jail or prison falls entirely on local taxpayers; 100% of the funding for this expense comes out of county and state general funds, respectively. In contrast, the cost of providing community treatment is shared equally with the federal government because county funds are matched by dollars from the federal entitlement programs Medi-Cal and Medicare.

SETTING	COST (annualized)
Full Service Partnership (Proposition 63)	\$24,000
Enhanced board and care	\$26,000 - \$153,000
Mental health rehabilitation center or	\$43,000 - \$78,000
Forensic skilled nursing facilities	\$150,000+
Napa State Hospital	\$185,000
Psychiatric inpatient bed	\$511,000
Jail housing	\$36,500 + treatment + court and legal costs
Inpatient unit in a jail	\$636,500 + court and legal costs
Prison housing	\$46,000
Prison treatment costs	\$2,000 - \$185,000

Scientific evidence, financial analysis of costs of current modes of treatment, and lack of access to federal financial participation mechanisms for mental health care all suggest that changes in mental health public policy could benefit patients, providers, and taxpayers.

References for Overview of Serious Mental Illness

- Atmaca M, Ozdemir H, Cetinkaya S, et al.: Cingulate gyrus volumetry in drug free bipolar patients and patients treated with valproate or valproate and quetiapine. *J Psychiatr Res* 41:821-827, 2007.
- Atmaca M, Yildirim H, Ozdemir H, et al.: Hippocampal IH MRS in patients with bipolar disorder taking valproate versus valproate plus quetiapine. *Psychol Med* 37:121-129, 2007.
- Cairns R, Maddock C, Buchanan A, et al.: Prevalence and predictors of mental incapacity in psychiatric in-patients. *Br J Psychiatry* 187:379-385, 2005.
- Cooke MA, Fannon D, Kuipers E, et al.: Neurological basis of poor insight in psychosis: a voxel-based MRI study. *Schizophr Res* 103:40-51, 2008.
- Damen J, Thuresson PO, Heeg B, et al.: A pharmaco-economic analysis of compliance gains on antipsychotic medications. *Appl Health Econ Health Policy* 6:189-197, 2008.
- Dell'Osso L, Pini S, Cassano GB, et al.: Insight into illness in patients with mania, mixed mania, bipolar depression and major depression with psychotic features. *Bipolar Disord* 4:315-322, 2002.
- Fitzgerald P, de Castella A, Arya D, et al.: The cost of relapse in schizophrenia and schizoaffective disorder. *Australas Psychiatry* 17:265-272, 2009.
- Gianfrancesco FD, Sajatovic M, Rajagopalan K, et al.: Antipsychotic treatment adherence and associated mental health care use among individuals with bipolar disorder. *Clin Ther* 30:1358-1374, 2008.
- Gilmer TP, Dolder CR, Lacro JP, et al.: Adherence to treatment with antipsychotic medication and health care costs among Medicaid beneficiaries with schizophrenia. *Am J Psychiatry* 161:692-699, 2004.
- Gunduz-Bruce H, McMeniman M, Robinson DG, et al.: Duration of untreated psychosis and time to treatment response for delusions and hallucinations. *Am J Psychiatry* 162:1966-1969, 2005.
- Haas GL, Garratt LS, Sweeney JA: Delay to first antipsychotic medication in schizophrenia: impact on symptomatology and clinical course of illness. *J Psychiatr Res* 32:151-159, 1998.

- Hassan M, Lage MJ: Risk of rehospitalization among bipolar disorder patients who are nonadherent to antipsychotic therapy after hospital discharge. *Am J Health Syst Pharm* 66:358-365, 2009.
- Knapp M, King D, Pugner K, et al.: Non-adherence to antipsychotic medication regimens: associations with resource use and costs. *Br J Psychiatry* 184:509-516, 2004.
- Lappin JM, Morgan KD, Morgan C, et al.: Duration of untreated psychosis and neuropsychological function in first episode psychosis. *Schizophr Res* 95:103-110, 2007.
- Law MR, Soumerai SB, Ross-Degnan D, et al.: A longitudinal study of medication nonadherence and hospitalization risk in schizophrenia. *J Clin Psychiatry* 69:47-53, 2008.
- Lew KH, Chang EY, Rajagopalan K, et al.: The effect of medication adherence on health care utilization in bipolar disorder. *Manag Care Interface* 19:41-46, 2006.
- Lysaker PH, Bell MD, Bryson GJ, et al.: Insight and interpersonal function in schizophrenia. *J Nerv Ment Dis* 186:432-436, 1998.
- Marcus SC, Olfson M: Outpatient antipsychotic treatment and inpatient costs of schizophrenia. *Schizophr Bull* 34:173-180, 2008.
- McClure RK, Phillips I, Jazayerli R, et al.: Regional change in brain morphometry in schizophrenia associated with antipsychotic treatment. *Psychiatry Res* 148:121-132, 2006.
- Mihalopoulos C, Harris M, Henry L, et al.: Is early intervention in psychosis cost-effective over the long term? *Schizophr Bull* 35:909-918, 2009.
- Mohamed S, Rosenheck R, McEvoy J, et al.: Cross-sectional and longitudinal relationships between insight and attitudes toward medication and clinical outcomes in chronic schizophrenia. *Schizophr Bull* 35:336-346, 2009.
- Moore GJ, Cortese BM, Glitz DA, et al.: A longitudinal study of the effects of lithium treatment on prefrontal and subgenual prefrontal gray matter volume in treatment-responsive bipolar disorder patients. *J Clin Psychiatry* 70:699-705, 2009.
- Olfson M, Marcus SC, Wilk J, et al.: Awareness of illness and nonadherence to antipsychotic medications among persons with schizophrenia. *Psychiatr Serv* 57:205-211, 2006.
- Owen GS, David AS, Hayward P, et al.: Retrospective views of psychiatric in-patients regaining mental capacity. *Br J Psychiatry* 195:403-407, 2009.
- Pini S, Cassano GB, Dell'Osso L, et al.: Insight into illness in schizophrenia, schizoaffective disorder, and mood disorders with psychotic features. *Am J Psychiatry* 158:122-125, 2001.
- Pini S, Dell'Osso L, Amador XF, et al.: Awareness of illness in patients with bipolar I disorder with

- or without comorbid anxiety disorders. *Aust N Z J Psychiatry* 37:355-361, 2003.
- Sarotar BN, Pesek MB, Agius M, et al.: Duration of untreated psychosis and its effect on the functional outcome in schizophrenia - preliminary results. *Psychiatr Danub* 20:179-183, 2008.
- Sassi RB, Brambilla P, Hatch JP, et al.: Reduced left anterior cingulate volumes in untreated bipolar patients. *Biol Psychiatry* 56:467-475, 2004.
- Stip E, Mancini-Marie A, Letourneau G, et al.: Increased grey matter densities in schizophrenia patients with negative symptoms after treatment with quetiapine: a voxel-based morphometry study. *Int Clin Psychopharmacol* 24:34-41, 2009.
- Sun SX, Liu GG, Christensen DB, et al.: Review and analysis of hospitalization costs associated with antipsychotic nonadherence in the treatment of schizophrenia in the United States. *Curr Med Res Opin* 23:2305-2312, 2007.
- Svarstad BL, Shireman TI, Sweeney JK: Using drug claims data to assess the relationship of medication adherence with hospitalization and costs. *Psychiatr Serv* 52:805-811, 2001.
- Weiden PJ, Kozma C, Grogg A, et al.: Partial compliance and risk of rehospitalization among California Medicaid patients with schizophrenia. *Psychiatr Serv* 55:886-891, 2004.
- Yen CF, Chen CS, Ko CH, et al.: Relationships between insight and medication adherence in outpatients with schizophrenia and bipolar disorder: prospective study. *Psychiatry Clin Neurosci* 59:403-409, 2005.
- Yen CF, Chen CS, Ko CH, et al.: Changes in insight among patients with bipolar I disorder: a 2-year prospective study. *Bipolar Disord* 9:238-242, 2007.
- Yen CF, Chen CS, Yen JY, et al.: The predictive effect of insight on adverse clinical outcomes in bipolar I disorder: a two-year prospective study. *J Affect Disord* 108:121-127, 2008.

Historical background and current state of mental illness treatment and science

The following information was sourced from the work and research of the Treatment Advocacy Center .

I. What percentage of individuals with serious mental illnesses are receiving no treatment?

SUMMARY: For the past 20 years, studies have consistently estimated that almost half of all individuals with schizophrenia or bipolar disorder are receiving no treatment for their mental illness at any given time. According to recent estimates of National Institute of Mental Health (NIMH), this means that approximately 3.5 million such individuals are receiving no treatment.

45 percent receive no treatment

In 2010, NIMH estimated that 40 percent of adults with schizophrenia and 51 percent of individuals with severe bipolar disorder receive no treatment in a one-year period. NIMH also estimated that there are 2.6 million adults with schizophrenia (1.1% of the adult population) and 5.1 million adults with severe bipolar disorder (2.2% of adult population). That means that there are 3.5 million adults with schizophrenia or bipolar disorder not being treated in the US on any given day.¹⁴

41 percent untreated within 30 days of hospital discharge

Mark Olfson et al. at Columbia University reanalyzed 2003 national Medicaid claims for 49,239 individuals with schizophrenia who were hospitalized. They found that 41 percent of the patients received no psychiatric follow-up treatment in the month following their discharge from the hospital. The strongest predictors of which patients would not get follow-up treatment were substance abuse and a history of not having received treatment prior to their hospitalization.¹⁵

¹⁴NIMH website. Prevalence of serious mental illness among U.S. adults by age, sex, and race. http://www.nimh.nih.gov/statistics/SMI_AASR.shtml; <http://www.nimh.nih.gov/statistics/1SCHIZ.shtml>; http://www.nimh.nih.gov/statistics/1BIPOLAR_ADULT.shtml; http://www.nimh.nih.gov/statistics/1MDD_ADULT.shtml; all accessed March 22, 2011 / ¹⁵Olfson M, Marcus SC, Doshi JA. Continuity of care after inpatient discharge of patients with schizophrenia in the Medicaid program: a retrospective longitudinal cohort analysis. *Journal of Clinical Psychiatry* 2010; 71:831–838.

2. Why individuals with serious mental illnesses often do not take their medications

SUMMARY: The single most significant reason why individuals with schizophrenia and bipolar disorder fail to take their medication is because of their lack of awareness of their illness (anosognosia). Other important reasons are concurrent alcohol or drug abuse and a poor relationship between psychiatrist and patient. Medication side effects, widely assumed to be the most important reason for medication nonadherence, are, in fact, a less important reason compared to the other factors cited.

Background: The failure of individuals with schizophrenia and bipolar disorder to take prescribed medications (usually antipsychotics and/or mood stabilizers such as lithium) is one of the most serious problems in psychiatric care. It often leads to relapse of symptoms, rehospitalization, homelessness, incarceration in jail or prison, victimization or episodes of violence. The failure to take medication is referred to as noncompliance or *nonadherence*; the latter is a better term. Nonadherence is also a problem for other medical conditions for which medication must be taken for long periods, including hypertension, diabetes, epilepsy, asthma, and tuberculosis. Nonadherence may be total but is more often partial; it has been suggested that partial adherence be defined as a failure to take 30 percent or more of the prescribed medication during the past month.¹⁶

The single best study of why individuals with severe psychiatric disorders do not take medication was done by Kessler et al.¹⁷ In interviews with those not taking medication, *the single most common reason, cited by 55 percent of the individuals, was that they did not believe they were sick.* They had anosognosia.

Other reasons for not taking medication were cited much less frequently:

- 7 percent “scared about hospitalization against own will”
- 6 percent “concerned about what others might think”
- 5 percent “not satisfied with available services”
- 1 percent “could not get an appointment”
- 0 percent “language problem”

¹⁶ Scott J, Pope M. Nonadherence with mood stabilizers: prevalence and predictors. *Journal of Clinical Psychiatry* 2002; 63: 384–390 / ¹⁷ Kessler et al, The prevalence and correlates of untreated serious mental illness. *Health Services Research* 2001; 36: 987-1007

The Kessler et al. study thus contradicts claims that many individuals with serious mental illnesses do not seek treatment because of fears of involuntary hospitalization, stigma or dissatisfaction with available services. It is commonly claimed that “if you make the psychiatric services attractive enough and culturally relevant, then individuals with serious mental illnesses will utilize them.” This appears to not be true. Very few individuals cited “not satisfied with available services,” “could not get appointment,” “language problem,” etc., as a reason why they were not in treatment. *The greatest reason for nontreatment by far was the person's lack of awareness of their illness.* Such individuals will not voluntarily utilize psychiatric services, no matter how attractive those services are, because they do not believe that they have an illness.

Lack of awareness of illness, also called anosognosia.

In a review, 10 of 14 studies that examined lack of awareness of illness and medication nonadherence in schizophrenia reported that the two are strongly associated.¹⁸

Other studies have also reported a strong association between lack of awareness and medication nonadherence. When impaired awareness of illness is compared with other reasons for medication nonadherence, it is invariably found to be the single most important reason. This is true for individuals with bipolar disorder as well as for those with schizophrenia.^{19,20}

Concurrent alcohol or drug abuse

The second most important reason for medication nonadherence in individuals with severe psychiatric disorders is concurrent substance abuse. This association has been reported in at least 10 studies (Lacro et al., op cit.).²¹

Poor relationship between psychiatric staff and patients

Every study that has examined this has found a poor relationship between psychiatric staff and patients to be a factor in patients' nonadherence to medications (Lacro et al., op cit.). It is often referred to as a poor therapeutic alliance. Such relationships include psychiatrists, psychologists, nurses, social workers and psychiatric aides in both inpatient and outpatient units. It involves things such as taking the time to listen to patients, treating them with respect, explaining things to them and involving them in treatment decisions insofar as this is feasible.

¹⁸ Lacro J, Dunn LB, Dolder CR et al. Prevalence of risk factors for medication nonadherence in patients with schizophrenia: a comprehensive review of recent literature. *Journal of Clinical Psychiatry* 2002; 63: 892--909 / ¹⁹ Faruqui RA, Andrews MD, Oyewole R et al. Clinical correlates of adherence to antipsychotic treatment in pre-discharge patients with schizophrenia [abstract]. *Schizophrenia Research* 2003; 60: 322 / ²⁰ Greenhouse WJ, Björn M, Johnson SL. Coping and medication adherence in bipolar disorder. *Journal of Affective Disorders* 2000; 59: 237 /

²¹ Hunt GE, Bergen J, Bashir M. Medication compliance and comorbid substance abuse in schizophrenia: impact on community survival 4 years after a relapse. *Schizophrenia Research* 2002; 54: 253--264

Medication side effects

This is often cited as the most important reason individuals with schizophrenia and bipolar disorder fail to take their medications. Studies, however, suggest that it is a much less important reason than the three reasons discussed above. In one review, only 1 out of 9 studies found a significant association between side effects and medication adherence in individuals with schizophrenia (Lacro et al., op cit.). "... Effects may have less influence on [medication] adherence than is currently presumed" (Day et al., op cit.)²².

Other factors

Other factors known to contribute to medication nonadherence in individuals with schizophrenia and bipolar disorder include cost of medication, no improvement in symptoms, confusion, depression, lack of access to medication because of being homeless or in jail and (for individuals with bipolar disorder) purposeful stopping of medication because they enjoy being manic.

3. The effects of involuntary commitment and involuntary medication on individuals with serious mental illnesses

SUMMARY: Some people have claimed that involuntarily committing or medicating individuals with serious mental illnesses causes devastating and long-lasting effects on the person and leads to widespread lack of cooperation with future treatment. Follow-up studies of such individuals do not support this claim. In most such studies, the majority of patients subjected to involuntary commitment or involuntary medication retrospectively agreed with the treatment or were neutral about it.

In 2005, researchers conducted face-to-face interviews with 76 assisted outpatient treatment (AOT) recipients to assess their opinions about the program, perceptions of coercion or stigma associated with the court order and quality of life as a result of AOT. After they received

²² Day JC, Bentall RP, Roberts C et al. Attitudes toward antipsychotic medication. *Archives of General Psychiatry* 2005; 62: 717–724, 2005.

treatment, interviewed recipients overwhelmingly endorsed the program.²³

- 75 percent reported that AOT helped them gain control over their lives.
- 81 percent said that AOT helped them to get and stay well.
- 90 percent said AOT made them more likely to keep appointments and take medication.

In 2004, interviews were conducted with 104 individuals with schizophrenia and related disorders regarding their feelings about involuntary (assisted outpatient) treatment. Such mandated treatment was regarded as being effective by 62 percent and as being fair by 55 percent of these individuals. Those who had awareness of their own illness (insight) were much more likely to regard mandated treatment as fair.²⁴

In 2003 in New York, 117 individuals with severe mental illness were followed up for 11 months after discharge from a psychiatric hospital. Those who perceived themselves as being forced to take medication (“high perceived coercion”) were compared with those who did not perceive themselves as being forced to take medication. At the end of 11 months, there were no differences between the two groups in their adherence to medication.²⁵

In 1996, 30 patients who had been forcibly medicated during their psychiatric hospitalization were interviewed by telephone one to two weeks later by individuals who had not been involved in their treatment. Eighty-seven percent of the patients had been diagnosed with schizophrenia or bipolar disorder. Among those who refused, 30 percent recalled having refused the medication because they had believed there was nothing wrong with them and 20 percent said they had refused because they had believed the medication was poison.

In 1995, 28 outpatients who had felt pressured or forced to take psychiatric medications within the preceding year were administered a questionnaire by their peers. They were part of a larger group of users of psychosocial rehabilitation centers. In reply to questions about how they felt about having been pressured to take medications, 9 (32 percent) were

²³ *Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment* (New York: Office of Mental Health, March 2005) / ²⁴ Swartz MS, Wagner HR, Swanson JW et al. Consumers' perceptions of the fairness and effectiveness of mandated community treatment and related pressures. *Psychiatric Services* 2004;55: 780–785 / ²⁵ Rain SD, Steadman HJ, Robbins PC. Perceived coercion and treatment adherence in an outpatient commitment program. *Psychiatric Services* 2003;54: 399–401

positive, 9 (32 percent) expressed mixed views, 6 (21 percent) reported no effect and 3 (11 percent) reported a negative effect. In addition, 12 patients (43 percent) said that the experience gave them a sense that people were looking out for their best interest. The authors also noted that "only a few respondents said that past experiences of pressured or forced medication had had any effect on their subsequent willingness to take medication."²⁶

5. Homelessness: One of the consequences of failing to treat individuals with serious mental illnesses

SUMMARY: People with untreated psychiatric illnesses constitute one-third, or approximately 250,000, of the estimated 744,000 homeless population in the United States. The quality of life for these individuals is abysmal. Many are victimized regularly. One study found that 28 percent of homeless people with previous psychiatric hospitalizations obtained some food from garbage cans and 8 percent used garbage cans as a primary food source.

In many cities, such as San Francisco, homeless people with severe mental illnesses are now an accepted part of the urban landscape and make up a significant percentage of the homeless who ride subways all night, sleep on sidewalks or hang out in the parks. These mentally ill individuals drift into the train and bus stations, and even the airports.

Many other homeless people hide from the eyes of most citizens. They shuffle quietly through the streets by day, talking to their voices only when they think nobody is looking, and they live in shelters or abandoned buildings at night. Some shelters become known as havens for these mentally ill wanderers and take on the appearance of a hospital psychiatric ward. Others who are psychiatrically ill live in the woods on the outskirts of cities, under bridges, and even in the tunnels that carry subway trains beneath cities.

A 2007 survey by the National Alliance to End Homelessness reported that there were approximately 744,000 homeless persons in the U.S. Numerous studies have reported that

²⁶ Lucksted A, Coursey RD. Consumer perceptions of pressure and force in psychiatric treatments. *Psychiatric Services* 1995; 46: 146–152.

approximately one-third of homeless persons have a serious mental illness, mostly schizophrenia or bipolar disorder. The percentage is higher among those who are chronically homeless and among homeless women and is lower among homeless families. If overall one-third of homeless persons are seriously mentally ill, that means that there are approximately 250,000 homeless persons with serious mental illnesses in the US.²⁷

The homeless population, especially homeless persons with serious mental illness, has increased steadily since the 1970s. This is seen in all major cities but also in smaller cities and towns.^{28,29} In 2006, Markowitz published data on 81 U.S. cities, looking at correlations between the decreasing availability of psychiatric hospital beds and the increase in crime, arrest rates and homelessness. As expected, he found direct correlations.^{30,31} This is consistent with past studies in Massachusetts and Ohio that reported that 27 and 36 percent of the discharges from state mental hospitals had become homeless within six months. It is also consistent with a study in New York that found that 38 percent of discharges from a state hospital had “no known address” six months later.³²

Officials think they are saving money by dumping patients out of the mental hospitals and onto the streets and public shelters, but they are not. “In 2001, a University of Pennsylvania study that examined 5,000 homeless people with mental illnesses in New York City found they cost taxpayers an average of \$40,500 a year for their use of emergency rooms, psychiatric hospitals, shelters, and prisons.³³”

Mentally ill homeless people are victimized regularly. In New York, 949 homeless men were interviewed regarding having been assaulted or injured. Twelve percent of the men were psychotic, and this group was significantly more likely than the nonpsychotic men to have been robbed, beaten, threatened with a weapon or injured (concussion or limb fractures). A study of homeless women in Baltimore found that nearly one-third of the women had been raped.³⁴

²⁷ Ohlemacher S. Study: 744,000 homeless in U.S. Associated Press archives, January 10, 2007, <http://www.ap.org/>, last accessed March 28, 2011 / ²⁸Hammack L, Adams M, Roanoke turns its focus on homeless. *Roanoke Times*, December 16, 2007 / ²⁹ Gagnon D. Role of Maine shelters in flux. *Bangor Daily News*, December 11, 2007 / ³⁰Markowitz FE. Psychiatric hospital capacity, homelessness, and crime and arrest rates. *Criminology* 2006; 44: 45–72 / ³¹ Belcher JR. Rights versus needs of homeless mentally ill persons. *Social Work* 1988; 33: 398–402 / ³² Belcher JR. Defining the service needs of homeless mentally ill persons. *Hospital and Community Psychiatry* 1988; 39: 1203–1205, ³² Drake RE, Wallach MA, Hoffman JS. Housing instability and homelessness among aftercare patients of an urban state hospital. *Hospital and Community Psychiatry* 1989; 40: 46–51 / ³³ Brinkman, P. Brown County Mental Health Center funding funnels into community placement; new trend impacts former, current institution residents. *Green Bay Press Gazette*, October 30, 2005, ³³ Mangano PF, Blasi G. Stuck on skid row: L.A. should do what other cities already are: move the homeless into permanent housing, and stop just managing the problem. *Los Angeles Times*, October 29, 2007 / ³⁴ Padgett DK, Struening EL. Victimization and traumatic injuries among the homeless: associations with alcohol, drug, and mental problems. *American Journal of Orthopsychiatry* 1992; 62: 525–534, ³⁴ Breakey WR, Fischer PJ, Kramer M et al. Health and mental health problems of homeless men and women in Baltimore. *Journal of the American Medical Association* 1989; 262: 1352–1357

5. Victimization: One of the consequences of failing to treat individuals with serious mental illnesses.

SUMMARY: Multiple studies have shown that individuals with severe psychiatric disorders are especially vulnerable to being victimized. This frequently involves acts such as theft of clothing or money, but also includes assault, rape or being killed. Women who have a severe psychiatric disorder are especially vulnerable. Some of the studies suggest that individuals who are victimized are less likely to have been compliant with their medication. This association is strongly supported by the 2002 North Carolina study by Hiday et al. that showed that individuals with severe psychiatric disorders who were on outpatient commitment, and thus were taking their medication regularly, were *victimized only half as often* as those who were not on outpatient commitment.

A 2009 review of victimization studies reported: “Rates of victimization among severely mentally ill persons were 2.3–140.4 times higher than in the general population.” Victimization occurred more frequently among individuals who were also abusing drugs and/or alcohol and among individuals who had the most severe symptoms.³⁵

A National Crime Victimization Survey interviewed 936 patients with “chronic and severe mental illnesses.” “More than one quarter . . . [of them] had been victims of a violent crime in the past year, a rate more than 11 times higher than the general population.” The authors suggested that the study “may underestimate victimization.”³⁶

In Los Angeles, 172 individuals with schizophrenia who were living in the community in stable housing were followed for three years. During that time, 34 percent of them were victimized by violent crimes (robbery, assault or rape). Individuals who were victimized were more likely to have had more severe symptoms, although medication compliance was not assessed in this study. The authors concluded: “This finding suggests that the most ill and vulnerable persons with schizophrenia are the most likely to be victimized.”³⁷

In San Francisco, 103 individuals with schizophrenia spectrum disorders and 36 with bipolar disorder were asked whether they had been victimized (by robbery, rape, mugging

³⁵ Maniglio R. Severe mental illness and criminal victimization: a systematic review. *Acta Psychiatrica Scandinavica* 2009;119:180–191 / ³⁶ Teplin LA, McClelland GM, Abram KM et al. Crime victimization in adults with severe mental illness. *Archives of General Psychiatry* 2005;62:911–921 / ³⁷ Brekke JS, Prindle C, Bae SW et. al. Risks for individuals with schizophrenia who are living in the community. *Psychiatric Services* 2001;52:1358–1366

or assault) within the past six months. At the time of the interview, all were living in residential homes. One-third of those with bipolar disorder and one-fifth of those with schizophrenia spectrum disorders had been victimized. Females were almost twice as likely to have been victimized compared to males.³⁸

In North Carolina, detailed information on victimization was obtained on 184 individuals with schizophrenia, schizoaffective disorder, and affective disorders, who were followed for one year. Eighty-five of the individuals were on outpatient commitment for part or all of the year and 99 were not. Victimization was classified as either a violent crime (e.g., assault, rape or mugging) or a nonviolent crime (e.g., burglary, theft of money or being cheated) against the psychiatrically ill person. Among the 85 individuals on outpatient commitment, 24 percent were victimized, while among the 99 not on outpatient commitment, 42 percent were victimized. The authors noted: “Furthermore, risk of victimization decreased with increased duration of outpatient commitment.” Individuals in the outpatient-commitment group were victimized significantly less often despite the fact that individuals in both groups received standard outpatient care and case management services.³⁹

The authors suggest that “outpatient commitment reduces criminal victimization through improving treatment adherence, decreasing substance abuse, and diminishing violent incidents” that may evoke retaliation.

6. Suicide: One of the consequences of failing to treat individuals with serious mental illnesses

SUMMARY: Suicide accounts for approximately 29,000 deaths each year in the United States. Studies suggest that at least 5,000 of the individuals who commit suicide have schizophrenia or bipolar disorder at the time of their suicides. Other studies indicate that most of these individuals were not receiving adequate psychiatric treatment at the time of their deaths. Adequate psychiatric treatment could save up to 5,000 lives per year.

Estimates of the completed suicide rate for individuals with schizophrenia range from **10 to 13 percent**, and for individuals with bipolar disorder the rate is about **15 percent**. This

³⁸ White MC, Chafetz L, Collins-Bride G et al. History of arrest, incarceration and victimization in community-based severely mentally ill. *Journal of Community Health* 2006; 31: 123–135 / ³⁹ Hiday VA, Swartz MS, Swanson JW et al. Impact of outpatient commitment on victimization of people with severe mental illness. *American Journal of Psychiatry* 2002; 159: 1403–1411.

rate is at least four times higher than similar studies from the period from 1913 to 1940, suggesting that the suicide rate has risen markedly since deinstitutionalization began.⁴⁰

One study examined the psychiatric histories in 134 individuals who committed suicide. It reported that 19 percent of these individuals had had symptoms of psychosis (e.g., delusions) in the month preceding their suicide. If this study is representative, then it means that almost one-fifth of all suicides are related to psychoses. Since there are about 29,000 suicides a year in the U.S., then at least 5,000 of them are psychosis-related⁴¹.

Several studies have reported that suicide among individuals with serious mental illnesses occur most commonly in individuals who are not taking their medication. For example, a study in Kentucky found that only 2 of 28 individuals with schizophrenia who committed suicide had evidence in their blood of having taken antipsychotic medication. Thus, 93 percent of them were not being treated.⁴²

7. How unawareness of illness (anosognosia) increases violent behavior in individuals with serious mental illnesses

SUMMARY: Unawareness of illness (anosognosia) is found in approximately half of all individuals with serious mental illnesses. It increases the likelihood that such individuals may become aggressive and violent. Unawareness of illness increases the chances that such individuals will not take medication, which therefore increases the person's symptoms and chances of becoming violent. The most important way to decrease violent behavior in individuals with serious mental illnesses is to make certain that they are being treated.

In the United States (five sites), 1,011 outpatients with severe psychiatric disorders were assessed for medication adherence and physically assaultive behavior over six months. Those who became physically assaultive were significantly more likely to have treatment nonadherence, to be sicker, to be a substance abuser, and to have a personality disorder.⁴³

⁴⁰ Caldwell C, Gottesman I. Schizophrenics kill themselves too: a review of risk factors for suicide. *Schizophrenia Bulletin* 1990;16:571--589, ⁴⁰ Goodwin FK, Jamison KR. *Manic-Depressive Illness* (New York: Oxford University Press, 1990), p. 230 / ⁴¹ Stephens J, Richard P, McHugh PR. Suicide in patients hospitalized for schizophrenia: 1913-1940. *Journal of Nervous and Mental Disease* 1999;187:10-14 / ⁴² Robins E. Psychosis and suicide. *Biological Psychiatry* 1986;21:665-672; ⁴³ Elbogen EB, Van Dorn RA, Swanson JW et al. Treatment engagement and violence risk in mental disorders. *British Journal of Psychiatry* 2006;189:354-360

In the United States (multi-site study), 1,906 individuals with schizophrenia and related disorders were prospectively followed and assessed for three years. Medication nonadherence was significantly associated with being violent, arrested and victimized.⁴⁴

In Ohio, 115 individuals with schizophrenia who had committed violent acts for which legal charges were incurred were compared to 111 individuals with schizophrenia who had no history of violent acts. The violent individuals had marked deficits in insight and were much more symptomatic. Compared to the nonviolent individuals, those who had been violent scored significantly lower on awareness of mental disorder, awareness of achieved effect of medications and awareness of social consequences of mental disorders.⁴⁵

In North Carolina, 331 severely mentally ill individuals who had been involuntarily admitted to a psychiatric disorder were assessed for their history of assaultive and violent behavior. The findings indicated that substance abuse problems, medication noncompliance, and low insight into illness operate together to increase violence risk.⁴⁶

In Massachusetts, 133 outpatients with schizophrenia were assessed for violent behavior over six months. During that period, 13 percent of the study group were characteristically violent, and this was associated with medication nonadherence. Seventy-one percent of the violent patients had problems with medication compliance compared with only 17 percent of those without hostile behaviors.⁴⁷

In New York, 60 male patients with psychosis who had been charged with a violent crime were assessed. Severity of community violence was strongly associated with poor insight, medication nonadherence and substance abuse.⁴⁸

⁴⁴ Ascher-Svanum H, Faries DE, Zhu B et al. Medication adherence and long-term functional outcomes in the treatment of schizophrenia in usual care. *Journal of Clinical Psychiatry* 2006;67:453–460, ⁴⁴ Grevatt M, Thomas-Peter B, Hughes G. Violence, mental disorder and risk assessment: can structured clinical assessments predict the short-term risk of inpatient violence? *Journal of Forensic Psychiatry and Psychology* 2004;15:278–292 / ⁴⁵ Buckley PF, Hrouda DR, Friedman L, et al. Insight and its relationship to violent behavior in patients with schizophrenia. *American Journal of Psychiatry* 2004;161:1712–1714 / ⁴⁶ Swartz MS, Swanson JW, Hiday VA et al. Violence and severe mental illness: the effects of substance abuse and nonadherence to medication. *American Journal of Psychiatry* 1998;155:226–231; ⁴⁷ Bartels SJ, Drake RE, Wallach MA et al. Characteristic hostility in schizophrenic patients. *Schizophrenia Bulletin* 1991;17:163–171 / ⁴⁸ Alia-Klein N, O'Rourke TM, Goldstein RZ et al. Insight into illness and adherence to psychotropic medications are separately associated with violence severity in a forensic sample. *Aggressive Behavior* 2007;33:86–96;

8. Violence Creates Stigma

SUMMARY: Stigma is one of the most important problems encountered by individuals with severe psychiatric disorders. It lowers self-esteem, contributes to disrupted family relationships and adversely affects the ability to socialize, obtain housing and become employed. In December 1999, the Surgeon General's Report on Mental Health called stigma "powerful and pervasive," and the Secretary of Health and Human Services added: Fear and stigma persist, resulting in lost opportunities for individuals to seek treatment and improve or recover.

Recent studies have demonstrated that stigma against people with mental illnesses has increased over the past half century and is still increasing. Multiple studies have also shown that the major cause of this stigma is the perception that some individuals with mental illnesses are dangerous. Given this fact, it seems self-evident that stigma will not be decreased until we decrease violent behavior committed by mentally ill persons, and this can only be done by ensuring that they receive treatment.⁴⁸

A. Stigma against mentally ill persons is increasing

In 2010, Pescosolido et al. assessed stigma against mentally ill persons, comparing results in a 2006 survey with a similar survey conducted in 1996. They reported that stigma had increased during that 11-year period and that "significantly more respondents in the 2006 survey than the 1996 survey reported an unwillingness to have someone with schizophrenia as a neighbor. . . . Our most striking finding is that stigma among the American public appears to be surprisingly fixed, even in the face of anticipated advances in public knowledge."⁴⁹

B. Violence is the major cause of this stigma

In 2008, a Harris poll reported that a majority of the public believes that violent behavior is a symptom of schizophrenia, and "roughly one in four Americans say they would feel uncomfortable around adults who have been treated for schizophrenia."⁵⁰

⁴⁹ Pescosolido BA, Martin JK, Long JS, Medina TR, Phelan JC, Link BG. "A disease like any other"? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. *American Journal of Psychiatry* 2010; 167: 1321–1330. Treatment Advocacy Center (www.treatmentadvocacycenter.org/)⁵⁰
⁵⁰ Schizophrenics battle stigma, myths in addition to disease. *USA Today*, June 8, 2008 /

A 1994 survey of Utah residents reported that 38 percent agreed that “people with mental illness are more dangerous than the rest of society.” In 1999, a man with schizophrenia killed two people in a library in Salt Lake City. According to a newspaper account, within hours Valley Mental Health began getting calls from frightened clients. “Clients were just sobbing,” said Connie Hines, public relations director for Valley Mental Health. They were afraid, she said, that the public would want to retaliate against them and that whatever progress had been made in the de-stigmatization of mental health had been set back years by the shooting.⁵¹

In 1999, a study reported that 61 percent of adults believed that an individual with schizophrenia was “very likely” (13 percent) or “somewhat likely” (48 percent) to do “something violent to others.”⁵²

In 1996, a study of American university students reported that reading a newspaper article reporting a violent crime committed by a mental patient led to increased “negative attitudes toward people with mental illness.”⁵³

A 1993 survey reported that more than half of people agreed with the statement that “those with mental disorders are more likely to commit acts of violence.”⁵⁴

9. Schizophrenia as a brain disease: Studies of individuals who have never been treated

There is a lot of misinformation regarding what is wrong with the brain in schizophrenia. Thomas Szasz, MD, once claimed that nothing is wrong and that schizophrenia is merely a myth. Peter Breggin, MD, has argued that people with schizophrenia bring the symptoms on themselves because of cowardice or failure of nerve. Daniel Fisher, MD said that schizophrenia is merely severe emotional distress and loss of social role brought on by trauma. Scientologists even claim that the symptoms of schizophrenia are caused by the drugs that are used to treat it.⁵⁵

⁵¹ Fraser ME. Educating the public about mental illness: what will it take to get the job done? *Innovations and Research* 1994; 3:29–31; ⁵¹ Jarvik E. Mental health clients fear growing stigma. *The Deseret News [Salt Lake City, Utah]*, April 24, 1999/ ⁵² Pescosolido BA, Monahan J, Link BG et al. The public’s view of the competence, dangerousness, and need for legal coercion of persons with mental health problems. *American Journal of Public Health* 1999; 89: 1339–1345/ ⁵³ Thornton JA, Wahl OF. Impact of a newspaper article on attitudes toward mental illness. *Journal of Community Psychology* 1996; 24: 17–24; ⁵⁴ Clements M. What we say about mental illness. *Parade Magazine*, October 31, 1993 / ⁵⁵ Szasz TS. *Schizophrenia: The Sacred Symbol of Psychiatry* (Syracuse: Syracuse University Press, 1976). Breggin PR, *The Psychology of Freedom* (Buffalo: Prometheus Books, 1980); ⁵⁵ Condon G, quoting Daniel Fisher on WTIC-TV, Hartford, Connecticut, April 6, 2005

Such statements indicate a profound ignorance about schizophrenia. Research has now clearly demonstrated that schizophrenia is caused by changes in the brain and that these can be measured by changes in both brain structure and brain function. More than 1,000 such research studies have been published. Schizophrenia is thus a disease of the brain in exactly the same sense that Parkinson's disease, multiple sclerosis, epilepsy and Alzheimer's disease are diseases of the brain.

The same thing can be said about some other severe psychiatric disorders, specifically bipolar disorder (manic-depressive illness), schizoaffective disorder, severe depression, autism and severe obsessive-compulsive disorder.

The following sections will briefly review the evidence representative of 120 studies indicating that schizophrenia is a brain disease.

A. Structural Abnormalities

The modern era in schizophrenia research can be dated to 1976, with the publication of the first research using the newly developed computerized axial tomography (CT) brain scans. Since then, at least 35 studies of brain structure have been done on individuals with schizophrenia who had never been medicated. All six studies that measured the size of the brain ventricles found them to be significantly enlarged. In addition to ventricular size, abnormalities in brain structure in never-treated individuals with schizophrenia have been reported for the frontal cortex, temporal cortex, hippocampus, amygdala, cingulate, thalamus, cerebellum, corpus callosum and septum pellucidum.⁵⁶

B. Neurological Abnormalities

Since 1976, at least 33 studies have reported significantly more neurological abnormalities in individuals with schizophrenia who had never been treated with antipsychotic medications compared to unaffected controls. The neurological abnormalities include Dyskinesias, which are spontaneous movements, usually involving the tongue, facial muscles or arms. Eleven

⁵⁶Johnstone EC, Crow TJ, Frith CD et al., Cerebral ventricular size and cognitive impairment in chronic schizophrenia, *Lancet* 1976;2:924; ⁵⁶Gur RE et al., Reduced gray matter volume in schizophrenia, *Arch Gen Psychiatry* 1999;56:905-911; ⁵⁶Cahn W et al., Brain volume changes in first-episode schizophrenia: a 1-Year follow-up study, *Arch Gen Psychiatry* 2002;59:1002-1010/

studies have demonstrated that such movements occur more often among never-treated individuals with schizophrenia than among unaffected controls. Eight recent studies have also reported that never-treated patients with schizophrenia have neurological abnormalities resembling those seen in Parkinson's disease, including rigidity, tremor and slowing of movements.⁵⁷

C. Neuropsychological Abnormalities

For almost two centuries, it has been observed that individuals with schizophrenia have deficits in some neuropsychological functions, especially memory, attention and planning (also called executive function). Since 1994, ten studies have been carried out on patients who had never received antipsychotic medications, confirming these observations. Several research groups studied individuals with first-episode schizophrenia, some of whom had never been medicated and some of whom had been briefly medicated, and reported that the never-medicated patients had significant neuropsychological deficits.⁵⁸

D. Neurophysiological Abnormalities

Electrical impulses are one method used to communicate between brain cells. Electroencephalograms (EEGs) have been used for many years to assess brain function in schizophrenia. Consistent with past studies, two recent studies used EEGs to examine sleep patterns in never-medicated individuals with schizophrenia, and both reported more abnormalities in the patients compared to the unaffected controls. Another technique commonly used in psychiatric research to measure neurophysiological function is a type of electrical impulse called an evoked potential. For example, a startle reflex, measured electrically, may be evoked by a loud sound. Three recent studies of evoked potentials have been carried out on never-medicated individuals with schizophrenia; all three showed significantly more abnormalities in the patients than in unaffected controls.

⁵⁷ Owens DGC, Spontaneous involuntary disorders of movement, *Arch Gen Psychiatry* 1982; 39: 452–461; ⁵⁷ Rogers D, The motor disorders of severe psychiatric illness: a conflict of paradigms, *Br J Psychiatry* 1985; 147: 221–232; ⁵⁷ Fenn DS et al., Movements in never-medicated schizophrenics: a preliminary study, *Psychopharmacology* 1996; 123: 206–210. ⁵⁸ See Brickman AM et al., Neuropsychological functioning in first-break, never-medicated adolescents with psychosis, *J Nerv Ment* 2004; 192: 615–622; ⁵⁸ Neuropsychological deficits in neuroleptic naïve patients with first-episode schizophrenia, *Arch Gen Psychiatry* 1994; 51: 124–131; ⁵⁸ McCreadie RG et al., Poor memory, negative symptoms and abnormal movements in never-treated Indian patients with schizophrenia, *Br J Psychiatry* 1997; 171: 360–363

Another measure of neurophysiological brain function is the recently developed transcranial magnetic stimulation (TMS), in which the brain is stimulated using magnets. A study of 21 neuroleptic-naïve individuals with schizophrenia reported them to be significantly different from 21 unaffected controls on some TMS measures. These studies suggest abnormal electrical and magnetic circuits in the brains of individuals with schizophrenia, evidence of neurophysiological dysfunction.⁵⁹

E. Cerebral Metabolic Abnormalities

The measurement of cerebral metabolic activity is comparatively new and technically complex. Three ways of doing this are by positron emission tomography (PET), single photon emission computed tomography (SPECT) and functional magnetic resonance imaging (fMRI). Since it is known that antipsychotic medications can affect these tests, it is important to use individuals who have not been treated whenever possible. Since 1991, 21 studies have examined cerebral metabolic abnormalities in individuals with schizophrenia never treated with antipsychotic medications. In comparison with control subjects, patients showed reduced activation in the right thalamus, the right prefrontal cortex and the parietal lobe . . . bilaterally. Of the 21 studies reported to date, all except one found more cerebral metabolic abnormalities in the individuals with schizophrenia compared to the controls.⁶⁰

⁵⁹ A Weike AI et al., Effective neuroleptic medication removes prepulse inhibition deficits in schizophrenia patients, *Biol Psychiatry* 2000; 47: 61–70; ⁵⁹ Valkonen-Korhonen M, Altered auditory processing in acutely psychotic never-medicated first-episode patients, *Brain Res Cogn Brain Res* 2003; 17: 747–758; ⁵⁹ Eichhammer P et al., Cortical excitability in neuroleptic-naïve first-episode schizophrenic patients, *Schizophr Res* 2004; 67: 253–259 / ⁶⁰ Braus DF et al., Sensory information processing in neuroleptic-naïve first-episode schizophrenic patients: a functional magnetic resonance imaging study, *Arch Gen Psychiatry* 2002; 59: 696–701 / ⁶⁰ Buchsbaum MS et al., Frontostriatal disorder of cerebral metabolism in never-medicated schizophrenics, *Arch Gen Psychiatry* 1992; 49: 935–942; ⁶⁰ Barch DM et al., Selective deficits in prefrontal cortex function in medication-naïve patients with schizophrenia, *Arch Gen Psychiatry* 2001; 58: 280–288.

LPS

REFORM
TASK
FORCE II

MARCH 2012

final recommendations