Privacy and Liberty: An Opportunity to Save Lives

A Policy Paper of the Opening Closed Doors Alliance and The Scattergood Foundation

1501 Cherry Street, Philadelphia, PA 19102
Phone: 215-831-3000 E-Mail: info@scattergoodfoundation.org Website: http://www.scattergoodfoundation.org

The below list of behavioral health-related organizations and their leaders have been deeply concerned and have worked to improve access and quality of behavioral healthcare in the United States.

We endorse the process by which this paper was developed, which involved several rounds of feedback to build consensus among a diverse group of stakeholders in behavioral health care. **Our organizations** recognize and value the ideas and suggestions summarized in this policy paper.

We stand ready to join your efforts to further develop meaningful, actionable improvements in behavioral health care in this country.

Cindy Baum-Baicker, PhD
Board Chair, Thomas Scattergood Behavioral Health Foundation
President of the Section on Couples and Family Therapy for the Division of Psychoanalysis (39) of the American Psychological Association
Michael Hogan, PhD
Hogan Health Solutions
Chair of the President's New Freedom Commision (2003)
Nadine Kaslow, PhD
President, American Psychological Association
Joe Pyle, MA
President, Thomas Scattergood Behavioral Health Foundation
Barbara Ricci
Board Chair, NAMI Metro NYC
Linda Rosenberg, MSW
President and CEO, National Council for Behavioral Health
Hank Schwartz, MD
Vice President, Behavioral Health, Hartford HealthCare,
Psychiatrist-in-Chief, Hartford Hospital
Lloyd Sederer, MD
Adjunct Professor, Columbia/Mailman School of Public Health
Medical Editor for Mental Health for the Huffington Post/AOL
Executive Leadership from the following hospitals:
The Institute of Living (a division of Hartford Hospital), Hartford CT
Natchaug Hospital, Mansfield, CT
Rushford Center, Inc., Middletown, CT
The Hospital of Central Connecticut Departments of Psychiatry located in:
New Britain, CT; Backus Hospital, Norwich, CT; and Midstate Medical Center, Meriden CT

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NAMI New York City Metro

Institute of Living
A Division of Hartford Hospital

Natchaug Hospital
A Hartford HealthCare Partner

SCATTERGOOD FOUNDATION

NATIONAL COUNCIL FOR BEHAVIORAL HEALTH
MENTAL HEALTH FIRST AID

Rushford
A Hartford HealthCare Partner

AMERICAN PSYCHOLOGICAL ASSOCIATION

The Hospital of Central Connecticut
A Hartford HealthCare Partner

Introduction

Tens of thousands of lives are lost every year to suicide and homicide by people in the throes of acute mental illness. Since the massacre in Newtown, CT, mental illness and the tattered fabric of services for people and families affected by the consequences of highly common mental disorders have been in the forefront of media and political attention. But too little has been done so far to make a difference for those whose fates lies ahead.

To remedy decades, truly centuries, of prejudicial neglect of people with serious mental (and addictive disorders) a great many things remain to be done. In this paper, however, we limit our focus to two areas of beliefs and values. We identify impediments to reducing not just to the risk of violence by individuals towards others, which though so publicly prominent and horrifying, is infrequent when measured against the incidence of suicide, disability and family despair that derives from limiting recovery from serious mental illness. We refer to matters of privacy and liberty, which we believe to be in our control – and thus in our hands to improve upon.

The material here builds upon the work to date of a group called ***The Opening Closed Doors Alliance*** with the support of the ***Scattergood Foundation*** (*The Tragedy of Mental Health Law: How privacy and liberty laws may be closing doors to families who can help*, Psychology Today, September 23, 2013, ***click here***; see also The Wall Street Journal, Op-ed, Sederer, LI, January 12, 2013, ***click here***).

While the risk of harm to self or others may never fully be eliminated, it can be reduced, often substantially. Our aim in this paper is to propose feasible solutions to reducing violence risk where successes can be realized in a near term horizon of 1-2 years. There are sensible policy options available to government leaders, advocacy groups, clinicians, and those impacted by serious mental illness. We hope that the solutions proposed here will help bridge the political and ideological divides that right now impede problem solving and achieving greater public safety.

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Privacy

In most Western countries, particularly the United States, the right to privacy has become tantamount to a sacred covenant. Privacy, moreover, has now taken on a far greater specter as technology has created an extraordinary capacity to gather and disseminate information. While privacy intrusions may help to protect national security,

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access to and the provision of information about our health can bestow benefits, not just spawn risks.

Information, like privacy, is not a categorical phenomenon. What is known, by whom, for how long, and with what capacity to distribute, exists on a gradient from the barely significant to the exceptionally invasive and potentially catastrophic to an individual and those within a few degrees of separation.

Privacy issues, like those of liberty, are central to the practice of psychiatry and mental health care. Privacy laws aim to protect the rights of individual consumers to control their health information. However, these laws have come under attack when families and clinical providers are unable to disclose or obtain important safety information that resulted in tragic outcomes (***click here***).[1]

Privacy is not a universal or unlimited right: laws about privacy vary from state to state in their content and more so in their interpretation and execution. We believe that privacy protections in mental health have both a needed application *and* limits – in both immediate, even life endangering, circumstances as well as over time.

The Cost of Untreated Mental Illness

Mental disorders are ubiquitous, with near to one in four people annually suffering with a mental illness[2] (like depression, bipolar disorder, schizophrenia and schizoaffective disorder, anxiety disorders, PTSD, eating disorders and borderline personality; this does *not* include substance use disorders, which are also extremely common).

Serious and persistent mental disorders are diseases of the brain. Repetitive episodes of illness damage the brain. Perhaps the most disquieting evidence of the impact of untreated mental illness is what has been termed DUP: Duration of Untreated Psychosis. Young people with early psychotic illness who do not receive effective treatment are incrementally more likely to have a life of disability as the years of untreated illness accrue.[3 4 5 6 7] We know, too, that for each episode of depression or mania a person experiences the likelihood increases exponentially of his or her experiencing yet another.[8] Not only is this demoralizing to all concerned - patient, family and doctor - it means that lives of productivity, relationships and contribution are lost. The notion that repetitive bouts of illness progressively damage a body organ is familiar: think of repeated heart attacks, uncontrolled diabetes and recurrent infections. The brain is not different.

The Consequences of Unfettered Privacy

Should an 18 year old with early psychosis, whether living at home or away at school, who refuses treatment have a right to keep information from family members about illness or treatment? Does a spouse, parent or sibling with an untreated mental illness

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that poses a danger to the ill person, or perhaps a danger to others, have the right to refuse sharing of information that could potentially do irreversible harm to others?

In many instances, families are or can be our early-warning system: They often see the fuse burning months before a crisis explodes. Yet families are too frequently sidelined by an ill relative not allowing their involvement in treatment. When treatment is delayed or necessary care is not delivered then everyone pays the price.

Key privacy laws and regulations in the United States

Health Insurance Portability and Accountability Act (HIPAA): Since 2003, the HIPAA Privacy Rule regulates the uses and disclosures of patients' personal health information by healthcare providers, health plans and healthcare clearinghouses. HIPAA permits these entities to disclose personal health information – without the patient's specific consent – for the purposes of treatment, payment, or healthcare operations. For most other disclosures, the provider or plan must receive the patient's specific authorization or prior agreement. In all cases, the covered entity may share only the minimum amount of information necessary.[9]

We hold that the HIPAA Privacy Rule, today, presents problems that increase risk of harm to self or others as a result of:

- *Inadequate understanding of HIPAA requirements by healthcare professionals*
- *Conflicting federal laws for the disclosure of substance use information*
- *Its standard for "Serious and imminent threat" disclosure*

HIPAA permits disclosure of information when an imminent and serious threat to the safety of the patient or others exists. Yet there are many other situations in which a person needs help but does not (yet) meet this standard: When a young adult living at home has stopped taking medications should his parents be notified, without consent, to help with resuming treatment? If a person presents at an ER with an emergency mental health condition, should the family be informed if consent is not forthcoming? Many family members and mental health providers have called for relaxing the "serious and imminent" standard to inform and support immediate, essential clinical care aimed at reducing the risk of harm to self or others.

Family Educational Rights and Privacy Act (FERPA): Healthcare information for adults is contained primarily in a medical record. For children and young adult students, however, school systems maintain records on services received at school health clinics as well as information on behavioral problems and infractions of school rules (such as using illegal drugs or alcohol).[10]

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FERPA outlines parents' and students' privacy rights in the context of these educational records; it extends privacy protections to the types of records not covered under HIPAA.

An important, if not well recognized, exception permits disclosure of the student's information, without consent, when knowledge of that information is necessary to protect the health or safety of that student or other individuals. FERPA differentiates between "educational records" and "treatment records" for students aged 18 or older, which are for use only by the persons providing healthcare treatment at that institution.

FERPA rules are important in the mental health privacy debate because a number of individuals involved in high-profile acts of violence had previously received evaluation or treatment at their colleges or universities.

As with HIPAA, FERPA is often misunderstood among the educational staff and healthcare professionals to whom it applies. The Departments of Education and Health and Human Services (November 2008) issued a "Joint Guidance" document[11] intended to clarify the intersection between FERPA and HIPAA; however, the complexity of the guidance and the numerous exceptions (along with the exceptions to the exceptions) continue to brew confusion.

What solutions to privacy problems are already in the public domain?

1. The recent HIPAA guideline clarifications from HHS

2. Advance Directives

3. The Helping Families in Mental Health Crisis Act

4. Mental Health First Aid

1. The recent HIPAA guideline clarifications from HHS: On February 21, 2014, the US Department of Health and Human Services released a "**Frequently Asked Questions**" (FAQ) document on disclosure of mental health information. The FAQ is a welcome response to the confusion over current privacy laws. It offers useful, new details on how the HIPAA Privacy Rule protects individuals' privacy rights with respect to their mental health information as well as in *what circumstances healthcare providers may communicate with patients' family members and others to enhance treatment and assure safety.*

Among other topics,[12] this FAQ explains when it is appropriate for healthcare providers to:

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- Communicate with a patient's family members, friends, or others involved in the patient's care;
- Consider the patient's capacity to agree or object to the sharing of their information;
- Involve a patient's family members, friends, or others in dealing with patient failures to adhere to medication or other therapy; and
- Communicate with family members, law enforcement, or others when the patient presents a serious and imminent threat of harm to self or others.

We believe this FAQ document if properly understood and disseminated can provide much-needed clarity about disclosure of information and thereby serve to help reduce instances where treatment is foreclosed, and illness worsens. It also conveys the need for clinical judgment, the value of parental concern and responsibility, and practical realities – all also welcome means of risk reduction by infusing common sense into decision-making. *However, while the HIPPA guideline clarifications represent an important advance, there remain significant obstacles to communication among clinicians and with families and caregivers that continue to limit optimal patient care.*

2. Advance directives for the disclosure of mental health information: Advance directives have existed for some time in general medical care. In a (relatively) healthy state of body and mind, a person, in the company of family and sometimes medical personnel, provides written choices about how that person wishes his or her treatment and care to be conducted if that person is no longer able to decide. The Advance Directive is safely stored by those named and by health professionals for use if and when needed.

- Advance Directives have the potential to become an important part of psychiatric practice. Forms specific to the challenges of psychiatric treatment (including involuntary hospitalization, medication and ECT) are called **Psychiatric Advance Directives (PADs).**[13] But **PADs** are not a panacea. Patients who are unable to appreciate they are ill may revoke them or write them hoping to prevent involuntary treatment in a crisis. PADs also can be disregarded by clinicians when they believe the requirements of the PAD are not consistent with needed and appropriate treatment. Nevertheless, they carry considerable moral weight and, when used to guide necessary treatment, PADs may contribute significantly to the patient's liberty interests.

3. Congressional Mental Health Bill:

The Helping Families in Mental Health Crisis Act (Formerly H.R. 3717): We anticipate that this bipartisan bill will be reintroduced by Congressman Timothy Murphy, PhD (R-PA and a trained psychologist), in the 2015 Congressional session. Rep. Murphy's bill

directly addresses the privacy issues presented by HIPAA and FERPA.[14] In a Republican Congress and with no other mental health bill active this is likely to be an important legislative action that warrants attention and efforts to ally with.

It has been over 50 years since we have seen legislative activity directed at improving the lives of people with mental illness and the public safety. We need legislative action, not political stasis, to support improvements in a mental health system widely regarded as flawed. A bipartisan bill that increases access to a variety of mental health services, appreciates the judgments of clinicians and families, and promotes public education about what to do when faced with acute mental illness ('mental health CPR' – see below) could assist with risk reduction and enhance treatment successes in this country.

4. Mental Health First Aid (MHFA):

It was not long ago that when a person collapsed on the street bystanders had no idea about what to do. Today we have CPR, where a simple, teachable response to a medical crisis can save lives.

The mental health counterpart to CPR is called Mental Health First Aid (***click here***).[15] Lay individuals, including family and friends, learn the signs of mental illness, how they can support a person in crisis, and how to help that person turn for further aid.

A national campaign to train hundreds of thousands of persons in MHFA is underway. MHFA represents yet another feasible strategy for reducing risk of harm from mental illness in our country.

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Professional colleagues and caring families need access and information to do what they want more than anything else: to help a patient or loved one get the help they need to be safe and recover.

Existing distinctions about protected information need to be reconsidered. At 18, the legal age of maturity, a brain affected by a serious depression or early psychotic illness has not yet fully developed its executive decision-making capacities: it is an immature brain and thus different from that of a 45 year old living with persistent illness (of any sort). As noted earlier, untreated illness is most damaging to youth whose brains are not fully developed.

We also know that young men in their late teens and twenties with untreated paranoid and psychotic illness are at significantly greater risk to be violent to others.[16] We know that suicide rates are highest with conditions like major depression, anorexia, bipolar

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disorder and schizophrenia (***click here*** for national suicide data).[17] Those people with trauma disorders, from war, childhood abuse, or disaster, are at greater risk for self-destructive behavior.[18] All these groups are at far greater risk of injury to self or others, and the progression of the mental illness, if the affected individual is using or abusing alcohol or non-prescribed medications.[19] To reduce the risk of harm, existing privacy constraints (real or misunderstood) need to recognize and accommodate to differences in illnesses and populations at greater risk.

There also are degrees of separation that exist between a person who does not want to voluntarily share information and others. We see this thinking in both Rep. Murphy's proposed bill and the HHS Guidance. Immediate family is different from a reporter calling an emergency room or a non-medical organization or schoolmate seeking information. Other professionals involved in a person's care, past or present, are different from a call from an insurance broker examining an application for benefits.

Laws and regulations as well as clinical practices are meant to serve, not create unnecessary and outdated impediments to serving. The landscape for privacy (and clinical practice) is different from the culture of the 1950s and 60s when doctors had the capacity for unbridled privacy (and liberty) intrusions. The landscape is also different today from the 1990s when HIPAA was passed and in the ways the law has come to be practiced today, which may be very different from its initial, intended aims.

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Liberty

No personal right seems to stir in Americans as much fire (and smoke) as liberty. It permeates our Constitution and Bill of Rights. It has particular salience for people with disabilities, especially those with mental illness.

Since Colonial times, a frequent approach to people with serious mental illness has been detention - first in poorhouses and asylums, and now in hospitals and increasingly in prisons. Dangerousness, to self or others as a result of mental illness, is one of a few circumstances under which people can be involuntarily detained under civil law (i.e., without having committed a crime). Involuntary commitment also is used in many states to compel participation in community care (Involuntary Outpatient Commitment—IOC, or Assisted Outpatient Treatment—AOT, the term we will use).

Many people "slip through the cracks" of the mental health system and fail to get care. The consequences usually are felt most significantly by the individuals themselves. Living with serious untreated mental illness is a painful state, and untreated illness

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predicts bad outcomes.[20] In addition to the burden to individuals and families; injury, disability and death; and the social costs, especially financial, are enormous, as media reports repeatedly depict.

Our view is that for people with the most serious mental illnesses, participation in quality mental health care is in their best interests, their family's best interests and in the best interests of the community. To reduce individual and community risk of violence we offer solutions that officials should consider now in designing mental health services. Our aim is to encourage Congress to act and advocates coming together to make that happen. There are services that are relevant, effective and can make a difference in in every state.

These solutions exist across the continuum from freely chosen participation in care to contested approaches like AOT. **We are guided by two principles** that are complimentary, and sometimes conflict:

- Ongoing participation in quality mental health care is fundamental to recovery (though we acknowledge there are cases where people recover without treatment). Care that is voluntarily chosen and collaborative is always preferable, and probably most effective.

- For people with the most serious mental illness, in crisis, their voluntary participation - while preferable - may not be possible. These individuals may believe nothing is wrong, or refuse care for reasons related to their illness or past experiences with treatment. Only when people are at serious risk but refuse to participate in treatment do we advocate for involuntary treatment, including AOT, and believe it should be used sparingly and respectfully.

These principles have a **critical corollary** that must be stated. An adequate, accessible health/mental health system that meets clinical needs early and collaboratively must exist if involuntary interventions are to be undertaken. An inadequate care system not only puts more people at risk to self and others, it also increases instances of coercion.

Why do we have these problems, and why do they persist?

For people with a mental health problem - and their families – today is "lose-lose" when it comes to recovery and liberty. Care is usually entered late, after a person's condition has persisted and worsened. In this flawed system, liberty concerns add to the problems (in unintended ways) by impeding access to care by high thresholds for involuntary interventions like hospital admission or AOT. Advocates, especially families but also clinicians, seeing how liberty laws (or their interpretation) can obstruct access to care,

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lament people deteriorating as they go untreated – or has been said, "dying with their rights on." [21]

Obtaining good mental health care is difficult, and the sad truth is that the more you need it, the harder it is to get. This is especially and tragically true for people who are experiencing psychotic conditions, like schizophrenia. These individuals may have difficulty realizing a problem exists or navigating an opaque treatment system that often acts in an uncoordinated, patchwork fashion. Getting good care under these conditions can be like trying to run a steeplechase race—when you are not feeling well. The hurdles are high and daunting and the course is long.

Even if all barriers are cleared and one has found the right clinician and team, it is only the beginning of a long road, especially for a serious mental (or addictive) disorder. While good treatments are available, they don't work for everyone or take time. And the most common treatment (medications) generally comes with unpleasant to dangerous side effects. While there may be fewer "downsides" to psychotherapy and rehabilitation, effective treatments for many and an important complement to medications, they are harder to find and require more time and investment.

Why are AOT and civil commitment generally so contentious?

Civil commitment is hard-wired into the US mental health system, with laws establishing inpatient commitment in all states and the District of Columbia.

The reasons for this include: The initial "mental health system" was essentially institutions (asylums, hospitals), which predated and were separate from general health care, which came centuries before the first health insurance plans. It was not until the creation of Medicaid and Medicare in 1965 that mainstream health care provided any substantial reimbursement for mental health treatment. Altered behaviors that are disturbing and occasionally dangerous led to confinement as a basic element in the fabric of the mental health system, and the laws that created and regulate it.

Courts and legislatures (including the U. S. Supreme Court) have defined and refined the terms of civil commitment. Over time, mental health laws have both narrowed and sustained civil commitment. For example:

- Limiting commitment to a "dangerous to self or others due to mental illness" standard and some form of grave disability, as determined by medical judgment, was articulated by the Supreme Court (O'Conner v. Donaldson, 1973);[22]
- Limiting the duration of commitment to very brief stays, and requiring court review of longer commitments.

- Requiring that those committed have access to treatment that offers a reasonable hope of resolving the problem(s) leading to confinement (Wyatt v. Stickney, Alabama).[23]

- The Olmstead v. L.C. decision (US Supreme Court, 1999), built on the Americans with Disabilities (ADA) Act, required states to develop community based alternatives for people who are institutionalized but judged to be capable of community life with support and treatment.[24]

- Most states have enacted laws establishing AOT (or a variant of compulsory participation in community care). AOT laws have been responses to persistently non-adherent individuals, "revolving door" patients (i.e., repeated ED and hospital stays), homelessness, and imprisonment. Often, AOT is not available even when laws allow it because professionals frequently do not use it. In addition, many AOT laws are passed without providing for adequate resources or community treatment options, which means intervening late, when actions are the most coercive and complex to implement.[25]

Involuntary mental health treatment can also reinforce the stigma of perceived dangerousness by establishing as a core mission of mental health services the confining and managing of dangerous people.

In other words, the mental health system is a mess. Paradoxically, for people with serious mental health problems, the ability to get comprehensive and quality care without a court order is often exceptionally difficult. Yet, we believe there are tangible ways by which the liberty and treatment interests of patients both can be advanced in communities and states.

Doing what can be done, now.

We outline below, five areas to **protect liberty *and* advance recovery**. If all were implemented, we could see a mental health system with earlier access, better outcomes, more collaborative opportunities to engage people in care, and less frequent involuntary commitment. Actions in these five ways could substantially decrease risk of self-harm or violence, progressive illness, and disability among people with serious mental illness:

1. **Innovations that enhance liberty interests, making current mental health practices more acceptable**

2. **Innovations in health and mental health services that can improve access and thus decrease the need for involuntary treatment**

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3. **Solutions for when things get really tough: People with mental illness and the criminal justice system**
4. **Emerging hope: new approaches for people with serious, emergent mental illness**
5. **When all else fails: Assisted Outpatient Treatment**

1. Innovations that enhance liberty interests, making current mental health practices more acceptable

Many innovations now exist that help people with serious mental illness manage their lives, and better use mental health services. A number of proven innovations, though not a definitive list, are in use in many communities and noted below. These low-cost, patient-centered alternatives should be available in every mental health system. Their use would make care more "consumer friendly" and collaborative, thereby reducing the barriers to participation that foster illness progression and risk over time.

- Advance Directives. Psychiatric Advance Directives (PADs) were described earlier. The challenges with using PADs relate to their being relatively new, policies about their use may not be clear, and written PADs may not be adequately communicated or kept current among a family or caregivers. While a person may retract the PAD at any time and physicians may override the wishes expressed in the PAD (if no other appropriate treatment options exist), PADs, nevertheless, are a valuable and growing resource for the guidance they provide.

- Wellness and Recovery Action Plans (WRAP). WRAP, developed by Mary Ellen Copeland, creates personal plans for life and recovery, useful at any stage of recovery from many mental illnesses.[26] This is not a legal document, but rather, a self-developed blueprint for living with illness. It is an important way for people with illness to take responsibility for their lives.

- *Common Ground*. This is a web-based approach developed by Patricia Deegan, Ph.D., to help people prepare for and participate in treatment (especially for medication) discussions and decisions with their physician and treatment team. Medication choices raise complex issues balancing effectiveness and side effects; yet we know that true collaboration between individuals and their physician/prescribers is the best predictor of medication adherence and treatment outcomes.[27]

2. Innovations in health and mental health services that can improve access and thus decrease the need for involuntary treatment

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Current health and mental health services can be improved to make them more acceptable to people who need care. None of the features we discuss are new but they have not achieved widespread implementation.

- Behaviorally competent ("collaborative") primary care. A major barrier to mental health care is that primary care physicians (PCPs) generally are not skilled in mental health treatments. Most people with mental disorders never go to specialty mental health care, even when referred; they do, however, often turn to primary care doctors for help. For depression, the most common and disabling mental illness, only about fifty percent of individuals with symptoms are detected and diagnosed by a PCP; of those who do only one in four get enough of the right care to produce desired results.[28] Collaborative Care specifies a well-proven method of providing basic mental health care within primary care.[29]

  Despite the nature of Collaborative Care (about 80 well designed research studies) it is rare in primary care delivery systems. Collaborative Care should be standard practice throughout this country. The ACA (Affordable Care Act) and the creation of Accountable Care Organizations may produce and align incentives to foster its widespread use.

- Open access. This includes walk-in appointments at mental health clinics as an alternative to the mind-numbing "intake process" of appointments offered weeks away. Services where a person can be seen on the day he or she seeks care would far better engage individuals in a treatment that, over time, can reduce risk of disability and harm. Open Access should be a standard of care for all clinic practices.

- Peer specialists. These are people with "lived experience" who, as well, are trained to serve as key members of community teams. Two national reports have endorsed peer services and supports: the first Surgeon General's Report in 1999 ***(click here)*** and the report of the President's New Freedom Commission in 2003 ***(click here).***[30] [31] Peer specialists are particularly helpful in engaging and retaining people in care, thereby preventing coercive interventions.

  Credentials and Medicaid reimbursement for peer specialists will be essential to continue to drive implementation of the use of peers, which should also be a standard of care available for people with serious mental illnesses.

- Housing First. Another innovative strategy becoming mainstream is Housing First. Safe, affordable housing is provided to homeless or long term

institutionalized people - without mandatory participation in mental health or addiction services. *After* these individuals are housed, efforts to engage people in recommended care then proceed. The evidence is abundant that people can be retained in apartments with this approach, which also reduces their morbidity and use of expensive medical services.[32]

- Accessible and Good Crisis Care. Deficiencies in psychiatric crisis care are a major obstacle to engagement in care and thus to recovery. *The paucity of crisis services in this country may represent one of the greatest omissions in the mental health care system, and thus an immediate opportunity for improvement.* The absence of crisis services sets the stage for later involuntary (costly) hospitalizations and overuse of Emergency Departments (ED). Good crisis care has several basic elements:
    - A 24/7 crisis line
    - Mobile crisis teams with trained clinicians, peer specialists and psychiatric backup – these are skilled personnel who can assess risk and take needed actions
    - Crisis respite (residential) settings where people can stay for a few days
- Assertive, mobile, team based care. Assertive Community Treatment Teams (ACT), or even briefer modifications of this exemplary approach, are far from commonplace in mental health care - a generation after its effectiveness was proven.[33] [34] No mental health system is complete without some clinically competent, seven day a week, mobile service that can treat and support people who need but cannot/will not come in for care. ACT must become an essential element in all mental health service systems; where it is absent, it should be introduced.

3. Solutions for when things get really tough: People with mental illness and the criminal justice system

More people with serious mental illness are now in jails or prisons than psychiatric hospitals. A range of solutions to this grave social problem have begun to emerge. They all involve some form of collaboration between mental health services, criminal justice programs, and/or the courts. They are in response to the inappropriate criminalization of behavior from (usually untreated) mental illness. They can be rendered at every stage of the criminal justice process, including: initial police contact, booking, time in jail, sentencing, and prison stays.

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Two of the best-established innovations for mentally ill offenders are Mental Health Courts and Crisis Intervention Teams (CIT).

- Mental Health Courts are not separate courts, but rather specialized court dockets or sessions that use the leadership role of the court to identify and offer services for mentally ill offenders, while providing options to traditional sentencing.[35] For example, a judge may offer participation in treatment as an alternative to a jail sentence. Mental Health Courts can provide leverage for staying in treatment that can keep mentally ill offenders out of chaotic and custodial jail/prison environments. Ironically, they sometimes provide access to and coordination of services not available before a person engaged in criminal activity.

- Crisis Intervention Training & Crisis Intervention Teams (CIT) are a special form of community policing. In CIT (first developed in Memphis as a partnership involving the Police Department, the local National Alliance on Mental Illness (NAMI) affiliate, and mental health agencies), dedicated teams of police officers receive specialized training in recognizing and resolving crises involving people with mental illness.[36] CIT programs have strong ties with mental health agencies, who immediately accept people into care. CIT has been credited with preventing police shootings and injuries to officers, reducing levels of inappropriate and costly incarceration of people with mental illness charged with (often minor) crimes, and reducing the time that officers spend in unproductive documentation and booking of people with mental illness into jails.

4. Emerging hope: new approaches for people with serious, emergent mental illness: First Episode Psychosis (FEP) interventions

Current systems of care for individuals with early psychotic symptoms are not working. Despite evidence that prolonged, untreated psychosis is associated with disability (and increased risk of harm to self or others) and significantly increased costs of care, long delays in entering care are common.[37]

Early intervention for young adults with psychotic illness must: 1) provide rapid entry into care, 2) deliver flexible, team-based care, and 3) emphasize maintaining functioning (e.g., remaining in school or work). Care is highly individualized and coupled with family and individual education, prudent medication management, and reducing/eliminating alcohol/drug use—especially cannabis.

FEP programs should be instituted in every state in this country. They should be a high priority in our efforts to improve care, reduce disability, and avoid the involuntary treatment associated with psychotic illness. This will not be easy: identifying young

people early in their illness and connecting them to care are challenging. But examples in this country and abroad show it can be done.[38]

5. When all else fails: Assisted Outpatient Treatment (AOT)

Assisted Outpatient Treatment (AOT) is a "…process whereby a commitment court, pursuant to a state's civil commitment laws, orders a person with mental illness to undergo community-based mental health care and related social services in lieu of compulsory institutionalization" ***(click here)***.[39]

Most states now have AOT laws, but there is relatively little actual use of it. AOT, as with other aspects of mental health reform, requires that beyond passing laws we must also make the "system" work.

A thorough review of AOT research and experience in multiple states by The RAND Corporation concludes that: 1) well-designed community mental health programs are effective in reducing hospitalizations and arrests; 2) AOT programs employing community services also have shown effectiveness; and 3) there is no evidence that the court order component of AOT has been shown to be effective (not shown to be ineffective).[40] These findings scarcely settle the contention surrounding AOT. Some seize on the research to conclude "AOT is ineffective; it's all about services." Others say "You often can't get the services without the court order; besides since it is *not* proven that the order is not effective, so AOT is necessary." Meanwhile, people needing care don't get it: first from an inadequate system and second because AOT, where it exists, is not adequately used.

The most comprehensive study of AOT involved the legislatively mandated evaluation of New York State's Kendra's Law program. The results of this study also do not settle the question of whether the court order is effective independent of the quality and intensity of services. The results are nonetheless informative. The evaluators note that New York's program was well structured and (especially in New York City) well-funded, and therefore that the results may not generalize. They report (***click here*** for the report)[41]:

- During AOT and after at least 12 months of participation, recipients:
    - Received more intensive case management services and had more consistent medication possession (as a proxy for receiving medications)
    - Were reported by case managers to have improved personal functioning in areas such as managing appointments, medications and self-care

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  - Reported neither more positive nor more negative experiences with mental health services than those reported by consumers *not* experiencing AOT
  - Were hospitalized less frequently and for less time than prior to participating in AOT

- After *at least* 12 months AOT participation, recipients continue to experience lower levels of hospitalization and higher levels of medication possession
- Recipients with 6 months or less of AOT experienced reduced hospitalization and increased medication possession *only* if they were receiving intensive case management services

These results *reveal a program effective for individuals with the highest level of needs as well as a clear relationship between a "sufficient" length of time under an AOT order (with intensive services)* and positive outcomes. The findings do not settle the question of whether intensive services and supervision *absent* an AOT order would be as good. Critics also point out that New York City's mental health system is famously complex, perhaps to make the point that *it is possible* that good, well-coordinated care without court orders might be possible in other communities.

How is Assisted Outpatient Treatment perceived by people who receive it? What are the implications?

While advocates on both sides may argue whether AOT is "good" or "bad," what do recipients actually think?

The MacArthur Foundation's Research Network on Mental Health and the Law studied the experiences of people involuntarily committed to inpatient treatment, interviewing over 1,000 people committed to hospital care in three different settings. They found first that "Legal status is only a blunt index of whether a patient experienced coercion in being admitted to a mental hospital. A significant minority of legally "voluntary" patients experience coercion and a significant minority of legally "involuntary" patients believe that they freely chose to be hospitalized." ***(click here)***.[42]

Thus, people's perceptions of their experiences are *not* so much related to their actual legal status but to their entire experience of care. In addition, the experience of feeling pressured and coerced even with 'voluntary' services may be more commonplace in the mental health system than many are willing to acknowledge.

The MacArthur group also *found that how people were treated during their care, including commitment, was perhaps more important to them than their status* under the

law. Patients who believe they have been allowed "voice" and treated by family and clinical staff with respect, concern and good faith report experiencing significantly less coercion than patients not so treated.

A second study examining people's experiences with AOT was the New York evaluation (discussed above). Interviews with people who had received AOT orders revealed that about half reported being angry or embarrassed by being placed under a court order. However, a majority (62%) reported being court ordered into treatment was a good thing for them. And, not surprisingly - and in line with the research overall - participants rated the services they received even more positively: 87% reported they were confident in their case manager's ability to help them and 90% agreed that the encouragement and pressure they experienced helped them keep treatment appointments and take medication.[42]

The evidence, in sum, suggests that people with the most serious mental illness who are not stable and have not participated in adequate care benefit from a substantial period (i.e., > 12 months) of closely supervised, respectful, community services, including intensive case management/Assertive Community Treatment and medication treatment, whether under AOT or not.

<u>The implications for both system leaders and advocates are:</u>

- Earlier intervention and flexible, patient centered and mental health services delivered with dignity to recipients should be available in all communities
- When or until good community services are present, AOT should be prudently used to ensure people receive continuous care. This means that where no AOT law exists, one is needed - unless demonstrated unnecessary because the needs of people with the most serious mental illness are met
- AOT laws are not of much use unless the conditions required for their effectiveness are present:
    - Procedures and programs to implement the law are in place, and local officials (mental health clinicians and courts) are willing to use them
    - Guaranteed access to intensive services are delivered
    - Participation for at least a year is possible

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CONCLUSIONS

The moment could not be more propitious for reforming mental health care laws and services than it is today. The public is restive, treasuries are being emptied by money poorly spent, the media continues to place front and center the serious and long standing problems of mental health services, and persons with mental illness (and their families) are not getting what they need to recover and build lives of contribution.

We believe that aspects of existing privacy and liberty laws and practices produce more problems than they solve. The pendulum has swung too far and has created impediments to the necessary provision of information about and engagement into care of too many people with serious mental illnesses.

In this paper we outlined feasible solutions to privacy and liberty constraints:

The privacy solutions in our reach are:

1. The recent HIPAA guideline clarifications from HHS
2. Advance Directives
3. The Helping Families in Mental Health Crisis Act (Murphy).
4. Mental Health First Aid

The liberty solutions in our reach are:

1. Innovations that enhance liberty interests, making current mental health practices more acceptable
2. Innovations in health and mental health services that can improve access and thus decrease the need for involuntary treatment
3. Solutions for when things get really tough: People with mental illness and the criminal justice system
4. Emerging hope: new approaches for people with serious, emergent mental illness
5. When all else fails: Assisted Outpatient Treatment

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We also believe that the actions advised in this paper can substantially reduce risk of violence, to self or others, illness progression, and disability that has cast too dark a shadow on American families and communities. There is so much we can do, now.

"The secret of the care of the patient is in caring for the patient" said Dr. Francis Peabody in 1925. His words not only orient us to what is important they also point to the method of doing so. We believe that ritually pursuing certain legal and practice proscriptions does not serve their intended purposes. What we can do now is to ask how we can better serve our patients, their families and communities. The answers are in plain sight.

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