Liberty and Recovery: Resolving a Mental Health Dilemma

A Review and Advocacy Guide

Introduction

No personal right has so much resonance for Americans as *liberty*. It permeates our Constitution and Bill of Rights. And it is a right that has particular salience for people with disabilities, especially mental illness. Since Colonial times, a major approach to people with serious mental illness has been detention—in poorhouses and asylums, in hospitals and increasingly in prisons. Presumed dangerousness—to oneself or others, and as a result of mental illness, is one of a relatively few circumstances under which people can be involuntarily detained under civil law (that is, without having committed a crime). This role of treatment facilities—while not unique in healthcare—has clearly affected the mission and complexion of mental health care. As an extension—or an alternative—to involuntary commitment to institutional care, civil court orders are unevenly used in some jurisdictions to compel participation in community care (this is termed Involuntary Outpatient Commitment—IOC, or Assisted Outpatient Treatment— AOT, the term we will generally use in this document).

Although these tools of involuntary confinement/treatment are in theory available in most places, many people "slip through the cracks" of the mental health system and fail to get care even with the mechanisms of commitment available. The consequences are usually felt most significantly by individuals themselves. Living with serious untreated mental illness can be very disturbing, and in the case of psychotic illnesses like schizophrenia it is now established that the "duration of untreated psychosis" (DUP) predicts bad outcomes. The longer one is psychotic without treatment, the greater the negative impact is likely going to be; an impact that could affect the rest of one's life. This personal burden of untreated mental illness is most costly to individuals and society. But we have also become accustomed to news about violence by individuals who almost certainly have an untreated mental illness. Even if the sensationalism of reporting is discounted, the impact of these cases is profound.

Our view is that for people with the most serious mental illnesses, *participation in quality mental health care is in their best interest, their family's and their community's*. But the barriers to getting good care are daunting. We hope this paper and toolkit will help advocates and families find and build solutions. We adopt a broad perspective— from approaches that may help individual families in crisis to systematic solutions that officials should consider in mental health reform. We also discuss solutions across the continuum from those we prefer—freely chosen participation in care—to approaches like AOT that are contested. We are guided by two principles that are both complimentary and sometimes in conflict:

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

- For people with the most serious mental illness who are in the throes of mental health crises, voluntary participation in care—while preferable—may not be possible. People may refuse care or not believe anything is wrong. When people are at serious risk but refuse to participate in treatment, we believe mechanisms like AOT should be used—sparingly and respectfully.

These principles have a corollary that must be acknowledged. An inadequate health/mental health system that often fails to meet needs early, collaboratively and well, *multiplies the damage of untreated mental illness but also makes approaches like AOT more prominent than they would be with a more effective system*. An inadequate system thus puts more people at risk, and increases the need to constrain liberty. We believe that the time is right to address these issues. Health reform and innovations ranging from new mental health approaches to improved technology offer the opportunity to improve the balance among these principles, yielding better access, better choices, and more liberty. We can move toward opportunities for recovery based on choice and collaboration. We will discuss ways to accelerate this shift. But in the meantime, we believe it is not right to deny care because we are unwilling to use AOT.

This paper and toolkit are intended to help advocates—from leaders in mental health care to families seeking care for a loved one to individuals just seeking better and more humane care—advance change.

Why do these problems and controversies persist?

For people with mental health problems—and for their families who want them to get well— we have a "lose-lose" system when it comes to recovery and liberty. Care is usually entered late, after a person's condition has worsened. The most intensive care often involves involuntary commitment to a hospital. In this imperfect system concerns about protecting liberty often have the unintended consequence of impeding access to care. The mental health community and elected officials sometimes seem to spend more time debating AOT than implementing the changes which would make it less necessary. Advocates for treatment, seeing how concerns about liberty seemingly delay access to care, lament people deteriorating without treatment and even "dying with their rights on." Advocates for mental health liberty decry "forced treatment" and "punitive institutionalization." Background on how a nonsensical system functions is necessary to understand why fundamental change and new approaches are needed.

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 the onset of a condition like schizophrenia, whose early symptoms may be both confusing and disturbing. These problems are insidious. They make it harder for us to realize a problem exists, more likely to keep it hidden because it is disturbing, and even more difficult to navigate a seemingly opaque care system that was established 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:

- Recognizing that one has a treatable problem is difficult—and may be made more challenging by the condition itself. Denial of illness is not uncommon and, for some, may even have a neurological basis (agnosonosia).

- Deciding to seek help is difficult. Do we admit we are not well? Am I crazy? Are there even things that will help? Will people think I am crazy if I ask? If treatment might help, will people think I am a mental patient? The internalization of stigmatizing attitudes is common and compounds the reality of the discrimination which individuals with mental illness face daily.

- Finding help can be a nightmare. We might start with our physician, but he might not be that much help. In the words of a parent: "Our children's physicians were wonderful medical professionals who had been helpful at every step of the way. When it came to dealing with a serious mental illness, they suddenly became incompetent."

- Although the barriers of insurance coverage are starting to break down, frequently in the past—and still today—getting one's health insurance to pay for brain health care has been challenging. Limits on what and how much would be covered, higher co-pays and deductibles and barriers to access, like insufficient mental health providers participating in the health plan, were commonplace.

- If all these barriers have been cleared and one has found the right provider and team, it is only the beginning of a new race, and it can be a marathon. While it is true that good treatments are available, they don't work for everyone. And the most common treatments (medications) can come with side effects that range from unpleasant to dangerous. There are fewer "downsides" to psychotherapy—which is an effective treatment for many and is often desirable in conjunction with meds, but is often harder to find.

Given these challenges, having a health system that seemingly imposes rather than removes barriers seems absurd. But it is reality.

Why is AOT, and civil commitment generally, so contentious?

Confinement to a hospital is not unique to mental illness. However, the role of involuntary commitment (usually, brief confinement to inpatient treatment) is greatly exaggerated in mental health care compared to other health care. For other health conditions, well established protocols do exist to isolate people with dangerous and communicable illnesses under controlled conditions A CDC publication discusses the issue (click here).[1] Detention with isolation for other medical conditions is sometimes used for protracted periods, as the following article about a man with infectious and drug-resistant tuberculosis illustrates (click here).

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[1] Siegel JD, Rhinehart E, Jackson M, Chiarello L, and the Healthcare Infection Control Practices Advisory Committee, 2007 Guideline for Isolation Precautions: Preventing Transmission of Infectious Agents in Healthcare Settings

Although there is a framework for detention of people with other health conditions, it is relatively rare, while civil commitment is hard-wired into the mental health system, with laws establishing inpatient commitment in all states and the District of Columbia.

The reasons for this are complex. The early "mental health system" was essentially limited to institutions (asylums, hospitals). These facilities predated and therefore were separate from health care—in fact the earliest asylums 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. And since mental illness manifests in altered behavior that can be disturbing and occasionally dangerous, confinement to hospitals for treatment became part of the fabric of the mental health system, and the laws that created and regulated it. Courts and legislatures (including the U. S. Supreme Court, in multiple cases) have defined and refined the terms of civil commitment. A full description is beyond this text, but changes in the laws regarding mental health care have both narrowed and sustained civil commitment. Key examples (with several relevant federal court cases noted) include:

- Limiting commitment to serious risks, not just a presumed need for treatment. The standard for commitment, usually "dangerous to self or others due to mental illness" and some form of grave disability, as determined by medical judgment, was articulated by the Supreme Court in the famous O'Conner v. Donaldson (1973) case;

- Various court cases and state laws were enacted limiting periods of commitment, and requiring court review of longer commitments;

- The requirement that people who are committed have access to treatment that offers a reasonable hope of resolving the problem leading to the commitment/confinement was articulated in the Wyatt v. Stickney case in Alabama. The case pointed to a right to treatment for hospitalized individuals which has never been fully established in law, and certainly not extended to community care.

- The Supreme Court's Olmstead v. L.C. decision in 1999 built upon the Americans with Disabilities Act by requiring states to develop community based alternatives for people who are institutionalized, but judged to be capable of community life with the appropriate supports and treatments. This decision established a preference for community care but did not make it a right for people not (yet) at risk for institutionalization.

- Most states have enacted laws establishing AOT or compulsory participation in community care. These laws have been enacted in response to persistently non-adherent individuals whose non-compliance leads to "revolving door" hospitalizations and, too frequently, to homelessness and imprisonment. These laws attempt to engage people in care in the community, but like inpatient commitment require a high level of need that is often similar to that required for hospital commitment.

There are obvious "side effects" that attend to involuntary commitment in the mental health system:

- It reinforces the stigma attached to mental illness and mental health care by linking mental health problems to dangerousness, and establishing that a core mission of mental health care is to confine and manage people who are dangerous. This distortion is baked into policy and public opinion. Statutes which allow commitment on the basis of "grave disability" or some equivalent, mitigate this risk to some degree. States such as Hawaii, which allow involuntary hospitalization of individuals who are "obviously ill," and in need of treatment obviate this risk altogether while risking a greater infringement of liberty interests.   Meanwhile, media coverage of violent acts by people with mental illness—often sensational—reinforces and perpetuates the complex and overblown relationship between mental illness and violence.

- Involuntary commitment associates mental health care with dangerousness and confinement. A hospital admission for any condition is significant, but most hospital care does not have this added burden of stigma.

- The treatments available for mental illness are imperfect. Although the efficacy of mental health interventions is comparable to that for other treatments, no treatment works all the time, many people do not get the best care, and the most frequently used treatments (medications) often have substantial side effects. Thus, confinement/civil commitment often results in people getting treatments that can help and also harm. (Mental health treatments do not generally differ from other health interventions in terms of their risk/benefit pattern. But when patient choice is abridged and there is a down-side to the interventions, the problems are magnified.)

- Controversy about AOT obscures a brutal reality: the health system—and the mental health system within it—is an opaque maze when it comes to accessing mental health care. People on average wait nine years from first symptoms of a mental health problem to getting care. The mainstream health system is usually not competent in detecting or treating mental health problems. Access to publicly funded mental health services such as that provided by mental health centers is often limited, and structured to prioritize care for those "most in need."

- Finally, AOT—a "last ditch" approach to getting people into care—is often not available even when laws allow it. The "controversial" nature of AOT has meant that even when laws are on the books, professionals often do not use them. And other conditions for effective use of AOT (e.g. guaranteed access to well monitored services) are often missing. In many cases, AOT laws were passed without providing for adequate treatment options.

The system is a mess. Our perspective is that liberty must be expanded for people with mental health problems, through real choices and the opportunity to get one's needs met without a court order. We also assert that engagement in quality mental health care is fundamentally important, particularly for people with the most serious conditions. These perspectives, seemingly in conflict, can in fact be aligned. *In the mental health system we seek, care would be early and based on personal preferences, and services would be welcoming to families. AOT would be more widely available and much less frequently used—because a system offering early and good care in a collaborative approach would result in less need for extreme measures.*

Our effort in this paper and toolkit is to outline tangible ways that the goals of liberty and engagement can both be advanced in communities and states. We want, and suggest progress on both. Our approach is to outline alternatives that increase engagement AND liberty, with examples and resources for advocates.

Given deeply divided views in the "mental health community," the turbulence of the environment in health care, and the complexity of change, some advocates will reject our approach because we endorse AOT, even though our ultimate goal is to have less involuntary care. Others may reject the approach because it is not solely focused on AOT. But we hope to provide perspectives and tools that allow advocates to work on improving engagement in care and/or on expanding liberty—or, preferably, both.

Do you think this section accurately introduces the concepts, problems, and controversial aspects regarding liberty and recovery?

⦿ Strongly Disagree   ⦿Disagree   ⦿Agree   ⦿Strongly Agree

Please add comments, suggestions, or anything you feel is missing:

To answer this question and provide feedback visit www.scattergoodfoundation.org/consensus-project

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An overview of our approach

Our approach is to offer guidance and advice on how to succeed in the difficult journey to get and to improve access. We will outline the best current knowledge about facilitating liberty and recovery in five areas. Each offers opportunities. If all were implemented, they would create a mental health system with earlier access, better outcomes, more collaborative opportunities to engage people in care, and involuntary commitment—probably used less frequently than it is used today—for those individuals for whom nothing else has worked:

- **Innovations that *enhance liberty interests, rendering current mental health practices more acceptable.***

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

- **Solutions for when things get really tough: People with mental illness and the criminal justice system;**

- **Emerging hope: the best new approaches for people with serious, emergent mental illness;**

- **When all else fails: Assisted Outpatient Treatment. The controversy, the data, and what to do.**

Do you agree with this general approach? The next five sections questions discuss the specific strategies of the approach.

⭕ Strongly Disagree   ⭕Disagree   ⭕Agree   ⭕Strongly Agree

Please add comments, suggestions, or anything you feel is missing:

To answer this question and provide feedback visit www.scattergoodfoundation.org/consensus-project

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Innovations that enhance liberty interests, rendering current mental health practices more acceptable

A number of innovations have been demonstrated to be effective in helping people manage their own lives, and to be empowered in their use of mental health services. We offer neither a definitive list nor a full treatment, but describe several tested innovations that are used in many communities and by many individuals. These low-cost, empowering alternatives should be available in every mental health system. Their use would make care more collaborative, and reduce barriers to participation for many. The alternatives we are suggesting are tested, widely used, and have resources available to aid in their adoption:

- *Wellness and Recovery Action Plans (WRAP).* WRAP, developed by Mary Ellen Copeland, is an approach to developing personal plans for life and recovery that may be useful to people at any stage or in any condition of recovery. The plan is not a legal document, but rather, a personal plan for living one's life (with mental health challenges). It is developed by the individual for herself; it may be developed and shared (e.g. in a self-help and mutual support group) or kept

private. WRAP is used in many states and countries and in many settings. It has been evaluated as effective. For resources on WRAP, click here.

- *Advance Directives.* Psychiatric Advance Directives (PAD) are a form of medical advance directive, which are provided for in some fashion in the law of every state. Generally, advance directives may specify how an individual wishes to be treated (e.g. at points in time when his competence to make decisions is impaired), or may name a person to act as his proxy decision maker. PAD's are intended to be prepared at a point in time when the person is composed and able to clearly think about preferences for care. Examples of issues which PAD's are intended to address are how people wish to be approached, treatment preferences e.g. medications that they prefer or do NOT prefer, and people they wish to be contacted about their treatment. Challenges with PADs largely relate to the fact that they are relatively new, that policies regarding their use may not be clear (even though laws exist to guide this) and that PADs may not be adequately communicated or kept current (e.g. a former therapist is named as a contact though she may no longer be involved in the individual's care). The greatest challenge surrounding PAD's is the paradox that in a psychiatric emergency, when the patient is not competent to refuse, a physician may override the wishes expressed in the PAD if there are no other appropriate treatment options. Still, PAD's are a valuable and growing resource that can be especially useful for the guidance they provide in times of crisis. For more information (click here).

- *Common Ground* is a web-based approach developed by Patricia Deegan, Ph.D. to help people prepare for and participate in treatment (e.g. medication) discussions and decisions with their physician/treatment team. The approach recognizes that medication treatments are first-line interventions in severe mental illness, that medication choices raise complex issues balancing effectiveness and side effects and that collaboration between individuals and their physician/prescribers is the best predictor of good medication treatment outcomes. Since medications are virtually the one constant in the treatment of severe mental illness and since their effects (both positive and negative) can be powerful, Common Ground cuts to the heart of care decisions to empower people. For more information click here and click here.

Do you think this section presents the most relevant innovations that enhance liberty interests while promoting recovery?

⭘ Strongly Disagree   ⭘ Disagree   ⭘ Agree   ⭘ Strongly Agree

Please add comments, suggestions, or anything you feel is missing:

To answer this question and provide feedback visit www.scattergoodfoundation.org/consensus-project

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

There are a number of ways that current health and mental health services can be improved to make its offerings more acceptable to people who need care. All of the features or improvements that we discuss below are in place somewhere. But few are present in most services, meaning that barriers are unnecessarily present for people who have passed the first hurdles and are ready to seek help. We discuss these improvements briefly, listing resources that are available to help motivated communities and providers to implement the changes:

- *Behaviorally competent ("collaborative") primary care*. Perhaps the greatest single barrier to care (after our own failure to recognize the need) is the fact that primary care physicians (PCP's) don't know what to do. For depression, the most common disabling mental illness (and a condition that is proven to be as reliably diagnosed as other common medical illnesses, if the right questions are asked), only about fifty percent of individuals with symptoms get an appropriate diagnosis from their PCP.   And of those who do, only about a quarter get enough of the right care to promise good results. Collaborative care is a well-proven method of providing basic mental health care within primary care. Its key elements are a co-located mental health professional, training and supports for the work (e.g. screening tools and adaptations in the medical record) and a psychiatrist available for consultation. Despite the well-proven nature of collaborative care (about 80 well designed research studies proving its effectiveness) it is missing in most primary care. As health care reform moves us toward the establishment of Accountable Care Organizations, the incentives may align to support the development of such collaborative practices. Perhaps the best-known resource for promoting collaborative care is at the University of Washington ([click here]).

- *Open access including walk-in appointments in mental health clinics.* The last thing someone needs after making the difficult decision to seek treatment is to be confronted by a bureaucratic and mind-numbing "intake process" with more questions about finances than about how you are feeling, followed by the announcement that the waiting list for an appointment is 6-8 weeks. Yet this barrier to care remains common place. Fortunately, things are beginning to change…in part because of the reality that the most common number of completed treatment visits in most mental health clinics is…ONE! This helps no one. But changing this paradigm and putting patients first is surprisingly hard work, requiring many changes to procedures and record keeping as well as to attitudes. The leading association of mental health organizations, the National Council for Behavioral Health, has a consulting practice with specialists who focus on such improvements. A result of their efforts—if pressure for change from payers and patients continues—should be an expectation that a person can be seen on the day that he comes in. Resources of the National Council are available by [clicking here].

- *Peer specialists as key members of community teams.* The role of self-help and peer support in and around the mental health system is scarcely a new development. Recovery Inc., founded by Abraham Low in 1938, was an early harbinger of this movement. It has been accelerating since publication of Judy Chamberlain's <u>On our Own</u> in 1978, and received a significant boost with two national reports that endorsed peer services and supports, the first Surgeon General's Report in 1999 (<u>click here</u>) and the report of the President's New Freedom Commission in 2003 (<u>click here</u>)[2,3]. While voluntary and unpaid self-help and peer support remain significant, peer services that are reimbursed as part of the treatment system continue to grow. The development of credentials and Medicaid reimbursement for peer specialists is a central driver of this trend, as is the closely related operation of consumer-owned-and-operated Recovery Centers that are present in a number of states. Peer specialists are particularly relevant to the challenge of engaging people in care. They can sometimes prevent the need for more coercive interventions because people needing care relate to their lived experience and appreciate the absence of a hierarchical relationship. Thus, peer specialists can often engage individuals fearful of involvement with mental health services. A robust peer presence is a crucial strategy in building responsive systems of care.

- *Housing First approaches for homeless individuals.* Another innovative strategy that is well on its way to becoming mainstream is Housing First[4] (<u>click here</u>). As the name implies, housing first provides safe housing to homeless people—without linking mandatory services participation to a place to live. When individuals are housed, efforts to engage people in recommended care can proceed. An analogue approach for people with substance abuse disorders has been termed "wet housing," in that people who are still abusing e.g. alcohol can be housed, as long as they follow other basic requirements of tenancy. The experience with both approaches is that they reduce homelessness and that many—but not all—individuals will agree to some participation in treatment once they are off the streets. Housing First approaches should be available in every community where there are homeless individuals with mental illness.

- *Good crisis care.* Deficiencies in psychiatric crisis care are an obstacle to engagement in productive, continuous care and thus to recovery, and can indirectly lead to increased involuntary hospitalization and to costly and problematic overuse of Emergency Departments (ED). Good crisis care has several basic elements:

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[2] U.S. Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.

[3] New Freedom Commission on Mental Health, Achieving the Promise: Transforming Mental Health Care in America. Final Report. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

[4] Tsemberis S, Gulcur L, Nakae M. Housing First, consumer choice, and harm reduction for homeless individuals with a dual diagnosis. Am J Public Health. 2004 Apr;94(4):651-6.

o   A 24/7 crisis line and "traffic control" function that uses technology to track the status of all individuals in crisis as well as access to both clinic and inpatient care, can assure timely access to these services, and also has the ability to deploy two alternative forms of crisis resolution services:

o   Mobile crisis teams with trained clinicians, peer specialists and psychiatric backup that can be deployed to where people in crisis are, with the skills to triage access to care, to manage transitional crises, and the ability to immediately place people in appropriate care via the call center described above, and:

o   Crisis respite residential settings that provide safe and supervised places where people in situational or psychiatric crisis that requires attention but not hospitalization can stay for up to a few days, until ready to return home.

An example of a well functioning system for managing crisis care is Georgia's statewide crisis system program (click here). An example of an innovative crisis respite program is New York City's Parachute program at (click here). Good systems of crisis care recognize that people in a mental crisis may come to an ED, but they move people quickly from these settings into more appropriate levels and locations for care.

- *Assertive, mobile, team based care.* In a sign of the slow pace of adaptive change, some locations in the U.S. do not have Assertive Community Treatment Teams (ACT) or modifications of this exemplary approach—a generation after its effectiveness was proven. 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 can not/will not come in for care. There are many resources on the ACT approach, for an example, click here.

Does this section present the relevant innovations to improve voluntary access?

⦿ Strongly Disagree   ⦿Disagree   ⦿Agree   ⦿Strongly Agree

Please add comments, suggestions, or anything you feel is missing:

To answer this question and provide feedback visit www.scattergoodfoundation.org/consensus-project

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

The fact that there are now more people with serious mental illness in jails or prisons than psychiatric hospitals is a well-known and tragic illustration of the failures of reform. Whether this failure is due to people with mental illness being caught up in dramatic increases in incarceration, poor coordination of mental health and criminal justice services or the failure of the mental health system to engage people at risk of criminal behavior is immaterial. The problem is a plain sign of a societal failure.

Fortunately, a range of solutions to this problem have begun to emerge. They all involve some form of collaboration between mental health programs, and criminal justice programs and/or courts. These collaborations recognize and begin to respond to the inappropriate criminalization of behavior that may result from (usually untreated) mental illness. They begin to repair the damage caused by inadequate access to care, and the unfortunate reality that individuals with mental illness fare worse at *every stage* of the criminal justice process: initial police contact, booking, time in jail, sentencing, and time in prison. A widely adopted framework for this work is the Sequential Intercepts model (click here), which identifies a continuum of opportunities to "intercept" people with mental illness who may be headed inappropriately into the criminal justice system, and to divert them to appropriate levels of care and supervision[5]. The "intercept points" range from initial contacts that police officers have on the beat, to booking in a jail, to trials and decisions by courts, to the transition of individuals already in correctional settings back to the community. Excellent resources on these activities are by clicking here and by clicking here.

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

- Mental Health Courts are not really separate courts, but rather specialized court dockets or sessions that use the leadership role of the court to find and align services for mentally ill offenders, while providing options to traditional sentencing. For example, a judge may offer participation in treatment (as an alternative to a jail sentence, if the treatment is completed successfully). Mental Health Courts can provide leverage for engagement in care that keeps mentally ill offenders out of chaotic and custodial jail/prison environments. Sometimes they also provide a way to access and coordinate services that, sadly, were not available to people before they engaged in potentially criminal activity. The National Center for State Courts offers excellent resources on Mental Health Courts (click here).

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[5] Munetz MR, Griffin PA. Use of the Sequential Intercept Model as an Approach to Decriminalization of People With Serious Mental Illness. Psychiatric Services. 2006; 57(4): 544-549.

- Crisis Intervention Training, Crisis Intervention Teams (CIT) may be described as a special form of community policing. In CIT—first developed in Memphis as a partnership involving the Memphis Police Department, the local National Alliance on Mental Illness affiliate and local mental health agencies—dedicated teams of police officers receive specialized training in recognizing and resolving crises involving people with mental illness. Full-fledged CIT programs have and expect strong collaboration from mental health care agencies, such as the commitment to immediately accept people into care. CIT has been credited with preventing police shootings as well as 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. Many resources on CIT are available, however the following link to the Memphis PD website connects to a description of the oldest, original CIT team (click here).

Do you think this section captures the most crucial solutions involving the criminal justice system (excluding AOT)?

    ⊙ Strongly Disagree   ⊙ Disagree   ⊙ Agree   ⊙ Strongly Agree

Please add comments, suggestions, or anything you feel is missing:

To answer this question and provide feedback visit www.scattergoodfoundation.org/consensus-project

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Emerging hope: the best 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 dysfunctional. Despite evidence that prolonged durations of untreated psychosis (DUP) are very bad for long term outcomes and significantly increase the cost of care, long delays in entering care are common. Ironically this appears in part to be due to the focus of public mental health systems on individuals with severe and persistent mental illness (SPMI) such that individuals with early psychosis may not meet eligibility criteria for state supported programs. Even if individuals are eligible, most publicly funded mental health programs are not tailored to and thus, not effective for, young people with emergent psychosis. Additional sources of delay in entering treatment lie in the difficulty newly psychotic individuals often experience in recognizing and acknowledging the problem

and difficulties in accessing care in the private realm as well. Early intervention for young adults with psychotic illness must: 1) reduce DUP via rapid entry into care; and 2) provide flexible team-based care, 3) emphasize maintaining functioning (e.g. supports to remain in school rather than drop out). Care is team based and highly individualized; elements include family and individual education, medication management with a strong emphasis on choice and finding acceptable treatments, and reducing/eliminating alcohol/drug use—especially cannabis. An excellent summary of the clinical rationale and research into early psychosis care by international leader Patrick McCorry and colleagues is found by clicking here[6]. State models for promoting early intervention into psychosis include Oregon (click here) and New York (click here).

Establishing FEP programs should be a high advocacy priority as a way to improve care, reduce disability, and avoid the bad outcomes and often involuntary treatment associated with psychotic illness. This will not be easy. The treatment approaches, though common sense, are new and often not well known, even to experienced staff. Ways to identify young people very early in their illness and to connect them to care are challenging. Inability to recognize one's condition and/or denial of illness, especially in its most virulent form (agnosonosia) leaves some people to reject prescribed interventions, Early FEP programs have learned to work very carefully and collaboratively with young people and their families on what care is acceptable to the individual. This is a delicate and complicated clinical task that requires the best in person-centered care.

Piecing together funding for FEP programs will be difficult. Public funding (e.g. Medicaid) is not customarily in place, ironically because people are not yet disabled. Private insurance does not customarily cover some FEP interventions. Even with parity some interventions (care coordination, collateral work with colleges or employers) may not be covered. The limited new support for FEP services in SAMHSA's 2014 budget is a very hopeful sign of attention to the problem. But this is an urgently important priority. There are few steps that can better reduce the disability and pain associated with untreated psychotic illness than creating responsive FEP care across America.

Do you think this section properly describes FEP interventions and their role in liberty and recovery?

○ Strongly Disagree   ○ Disagree   ○ Agree   ○ Strongly Agree

Please add comments, suggestions, or anything you feel is missing:

To answer this question and provide feedback visit www.scattergoodfoundation.org/consensus-project

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[6] McGorry PD, Killackey E, Yung A. Early intervention in psychosis: concepts, evidence and future directions. World Psychiatry. 2008; 7(3): 148-158.

When all else fails: Assisted Outpatient Treatment.
The controversy, the data, and what to do.

What is it?

Involuntary Outpatient Commitment (IOC) or Assisted Outpatient Treatment (AOT) is defined by the American Association of Community Psychiatrists as "the 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). Thus, the essential elements of AOT are:

1. state law providing for outpatient commitment,
2. mechanisms (e.g. court procedures) to put it in place and
3. available care and services.

Status of Involuntary Outpatient Commitment

Outpatient commitment has generally moved from being a hotly contested topic played out via protracted debates about establishing state laws, to today's reality in which most states have laws on the books, but there is relatively little actual use of AOT. (The Treatment Advocacy Center, a proponent of IOC says 45 states have IOC laws [click here]. An earlier, undated report from the Bazelon Center, which opposes IOC cites 37 states that have such laws [click here]). Both proponents and opponents say the laws are not used very much. *The emerging challenges with AOT, as with other aspects of mental health reform, extend beyond passing laws to making the "system" work effectively.*

What the research says

The research on the effectiveness of IOC is equivocal. Only a few randomized, controlled studies have been done on IOC's effectiveness, and they diverge in their findings.   One study, done at Bellevue Hospital in the 1990's, found little effectiveness of IOC (click here)[7]. The other study conducted about the same time in North Carolina, showed positive results, with fewer hospitalizations for the group receiving IOC (click here)[8].

In a very thorough review of IOC research and experience in multiple states, The RAND Corporation concludes that: 1) there is clear evidence for effectiveness of well-designed community mental health programs (e.g. reduced hospitalizations and arrests); 2) IOC programs employing such programs have also shown effectiveness; and 3) there is no evidence that the court order component of IOC is itself effective.

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[7] Steadman JH, Gounis K, Dennis D, Hopper K, Roche B, Swartz M, Robbins PC. Assessing the New York City Involuntary Outpatient Commitment Pilot Program. Psychiatric Services. 2001; 52(3): 330-336.

[8] Swartz MS, Swanson JW, Wagner HR, Burns BJ, Hiday VA, Borum R. Can Involuntary Outpatient Commitment Reduce Hospital Recidivism?: Findings From a Randomized Trial With Severely Mentally Ill Individuals. Psychiatric Services. 1999 156(12): 1968-1975.

These findings scarcely settle the question. Advocates on both sides of the issue "cherry pick" the findings, emphasizing those favorable to their point of view and ignoring those they disagree with. On the overall findings, opponents seize on the research to conclude "AOT is ineffective; it's all about services." Proponents say "You often can't get the services without the court order, and besides it is not proven that the order is not effective, so IOC is necessary." So controversy continues. Meanwhile, people needing care don't get it; first from an inadequate system and second because AOT, where it exists, is not used.

The most comprehensive study of AOT involved a careful evaluation of New York State's Kendra's Law program. The results of the study do not settle the question of whether the court order component is effective independent of the quality and intensity of services, adding fuel to the arguments on both sides. 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:

- During AOT and after at least 12 months of participation, recipients:

  o Received more intensive case management services and had more consistent medication possession (possession of medication is a proxy for receiving medications, which could not be feasibly assessed).

  o Were reported by case managers to have improved personal functioning in areas such as managing appointments, medications and self-care.

  o Reported neither more positive nor more negative experiences with mental health services than those reported by consumers not experiencing AOT.

  o 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.

- However, recipients with 6 months or less of AOT experienced reduced hospitalization and increased medication possession *only* if they were receiving intensive case management services.

The full report is found by [clicking here](#)[9].

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[9] Swartz, MS, Swanson, JW, Steadman, HJ, Robbins, PC and Monahan J. New York State Assisted Outpatient Treatment Program Evaluation. Duke University School of Medicine, Durham, NC, June, 2009

These results reveal a program that is effective for individuals with the highest level of needs and some of the worst outcomes absent AOT (Not many more than about 1,000 individuals were under AOT orders at any one time in NYC). The results show a clear relationship between a "sufficient" length of time under an order/with intensive services, reinforcing the common sense idea that a period of stability provides a strong foundation for subsequent and ongoing recovery. 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, to make the point that it is possible that good, well-coordinated care without court orders might be sufficient to secure participation of many individuals. There is no way as yet to test these assertions.

A crucial consideration: How is Assisted Outpatient Treatment perceived by people who receive it? What are the implications?
This issue is important from several perspectives. First, the experiences and perceptions of people who actually receive AOT are crucial; advocates on both sides are exercised about whether AOT is "good" or "bad," but what do recipients actually think? Second, to the extent we have information on what recipients find positive and negative, this should shape how programs are designed and delivered.

Several research studies inform us on these issues. 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 who were 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). Thus, people's perceptions of their experiences are not so much related to their actual legal status, as to their entire experience.   In addition, the experience of feeling pressured and coerced, while clearly not universal, may be more commonplace in the mental health system than many people are willing to acknowledge. These sobering findings go to the heart of the mental health system's roots in institutional care and the imperative of rebalancing toward liberty, choice and autonomy.

The MacArthur group also found that *how people were treated in the process of care, including commitment,* was perhaps more important to them than their status under the law. To quote the researchers: "The amount of coercion a patient experiences in the mental hospital admission process is strongly associated with the degree to which that process is seen to be characterized by "procedural justice." That is, patients who believe they have been allowed "voice" and treated by family and clinical staff with respect, concern, and good faith in the process of hospital admission, report experiencing significantly less coercion than patients not so treated. This holds true even for legally "involuntary" patients and for patients who report being pressured to be hospitalized" (same source as above). This finding is both self-evident and profoundly important. How people are treated—and how they perceive they are treated—is universally significant. And it is even more salient when liberty is at risk, and when conditions of discrimination and stigma exist.

A second study examining people's experiences with IOC was the New York evaluation discussed earlier. Interviews with people who had received AOT orders revealed that about half reported being angry (54%) or embarrassed (53%) by being placed under a court order. However, a majority (62%) reported that in sum, 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 (report accessed by clicking here pages 20-21)[10].

Implications for Involuntary Outpatient Commitment programs from the research: What administrators should do? What advocates should push for?
The evidence 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 (e.g. 12+ months) of closely supervised community services including intensive case management/Assertive Community Treatment and medication treatment, whether under IOC or not. Logic suggests that if these individuals had received earlier, better and more collaborative care their dire circumstances and the need for IOC might have been avoided.

Clinical experience also suggests that some people with severe mental illness will not participate in intensive services without significant inducements, possibly including an IOC order. The implications for both system leaders and advocates are:

- Earlier intervention, and mental health services that are flexible, consumer friendly and empowering (as discussed in this paper) should be available in all states.

- When or until these services are present, IOC should be used to ensure people get continuous care. This means that where no IOC law exists, one is needed—unless it is clear that it is unnecessary because the needs of people with the most serious mental illness are met.

- IOC 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 officials, courts) are willing to use them;
    - Intensive services are provided with guaranteed access;
    - Participation for at least a year is possible.

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[10] New York State Office of Mental Health. Kendra's Law: A Final Report on the Status of Assisted Outpatient Treatment. 2005.

- Despite—in fact *because of* the stigma associated with mental health care, especially court-ordered care--the dignity, respect, caring and kindness with which people are treated during the IOC process and throughout any court-ordered care is crucial, Providers should accept the responsibility of heightened attention to the perceptions and concerns of people under AOT orders.

Do you think this section accurately describes the current status of and research about AOT?

⊙ Strongly Disagree   ⊙ Disagree   ⊙ Agree   ⊙ Strongly Agree

Please add comments, suggestions, or anything you feel is missing:

To answer this question and provide feedback visit www.scattergoodfoundation.org/consensus-project

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Resources

Programs & Organizations

1. National Resource Center on Psychiatric Advance Directives http://www.nrc-pad.org

2. University of Washington Advancing Integrated Mental Health Solutions (AIMS) Center http://uwaims.org/

3. The National Council for Behavioral Health http://www.thenationalcouncil.org/

4. Georgia's Statewide Crisis System Program http://www.behavioralhealthlink.com/

5. New York City Department of Health and Mental Hygiene Parachute Program (Crisis Respite Program) http://www.nyc.gov/html/doh/html/mental/parachute.shtml

6. NAMI's Program of Assertive Community Treatment http://www.nami.org/Template.cfm?Section=ACT-TA_Center&template=/ContentManagement/ContentDisplay.cfm&ContentID=132547

7. The Council of State Governments Justice Center http://csgjusticecenter.org/

8. SAMHSA's GAINS Center for Behavioral Health and Justice Transformation http://gainscenter.samhsa.gov/

9. National Center for State Courts: Mental Health Courts http://www.ncsc.org/topics/problem-solving-courts/mental-health-courts/resource-guide.aspx

10. Memphis Police Department Crisis Intervention Team (CIT) http://www.memphispolice.org/Crisis%20Intervention.htm

11. Oregon State Early Psychosis Intervention Program http://www.oregon.gov/oha/amh/pages/services/easa/main.aspx

12. New York State Early Psychosis Intervention Program http://www.omh.ny.gov/omhweb/Press/ontrackny.html

Articles & Summaries

1. Article from The Wall Street Journal, March 1st 2013: Dangerous TB Patient Detained on U.S. Border http://online.wsj.com/news/articles/SB10001424127887323978104578332461533970412

2. WRAP and Recovery Books http://www.mentalhealthrecovery.com/

3. Summary of Common Ground from the Agency for Healthcare Research and Quality of the Department of Health and Human Services http://www.innovations.ahrq.gov/content.aspx?id=2870

4. American Association of Community Psychiatrists Position Paper on AOT http://www.communitypsychiatry.org/publications/position_statements/ioc.aspx

5. Treatment Advocacy Center's Summary of State AOT Laws http://www.treatmentadvocacycenter.org/solution/assisted-outpatient-treatment-laws

6. Bazelon Center's Summary of State AOT Laws http://www.bazelon.org/LinkClick.aspx?fileticket=CBmFgyA4i-w%3d&tabid=324

7. MacArthur Research Network on Mental Health and the Law: The MacArthur Coercion Study. 2004 http://www.macarthur.virginia.edu/coercion.html