



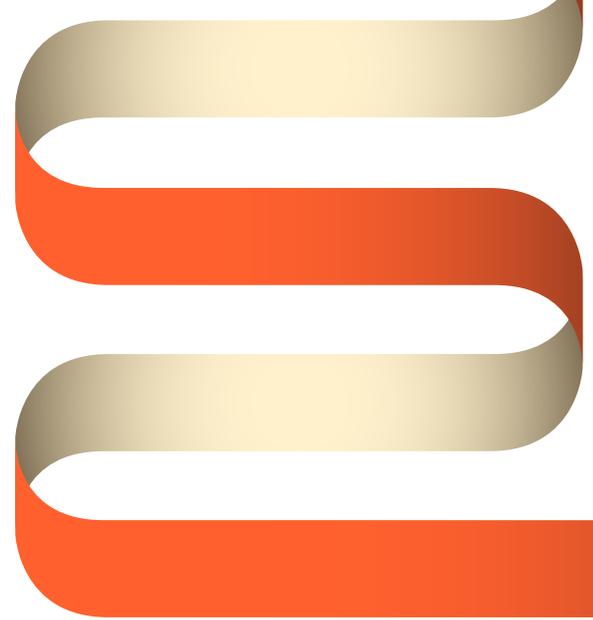
Compassion



Safety



Rights



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The issue of the intersection of compassion, safety, and rights in mental health has been one I have thought about deeply for years. Some of my first work in mental health was as a human rights investigator in a state psychiatric hospital system. I am a person with a major psychiatric diagnosis, and the parent of a grown child with a major psychiatric diagnosis who was first diagnosed as an adolescent. I have worked as an advocate and leader for two peer run organizations, as an advocate employed by a state government, and as an advocate for Mental Health America. I have been involuntarily committed for inpatient treatment, albeit briefly, and I am a survivor of attempted suicide. On

numerous occasions I have been given the unlawful choice to be admitted as an inpatient voluntarily or involuntarily (you can either give informed consent or you can't). During my life I have had six friends end their lives and have known many more. I have been forced to look at these issues from many sides.

I want to bring all of those perspectives plus the opinions of others and the most current research and law together in order to examine the complex relationship between compassion, safety, and rights. Going into this discussion it is my feeling that they are not mutually exclusive but they are often in conflict when we deal with real people.

"The purpose of human life is to serve, and to show compassion and the will to help others."

-Albert Schweitzer



Compassion is a complicated issue when we think of it in the context of mental health. What one person feels as true compassion may feel intrusive or even cruel to another. Almost everyone who gets involved in the mental health system does so from a feeling of compassion. It is a deep seated quality, driven by our feeling of mutual humanity. When we abandon compassion the world becomes a dark, sometimes evil place. It is a highly individualistic feeling, based on our personal understanding of the experiences and feelings of others. It can be a tricky emotion, think of how many times we do something to protect our children or loved ones from getting hurt. Sometimes it comes back on us, causing them to be angry rather than grateful. Ask any parent of a teenager.

What do we do when our loved one is profoundly disturbed, paranoid, anxious and fearful to leave their home? What does a doctor do when someone is actively psychotic, unable to give informed consent, but comes into a crisis facility with a legal advance directive saying they do not want to take anti-psychotic medications? What do we do when someone with a long history of dangerousness and hospitalizations shows signs of increasing symptoms? What do we do when our grown child lives in filth, eats poorly, and often spends days or weeks on the streets?

The intersection of compassion, safety, and rights often seems to come together around the issue of involuntary treatment. There are hundreds of scenarios that lead to involuntary treatment, but when is it appropriate, when is it legal, and when is it right? The first place to look is the law. The basic standard for placing someone in involuntary inpatient treatment is imminent danger to self or others due to mental illness, the questions are what constitutes "imminent", "danger" and "mental illness"? Some courts and state laws have taken a broad view that includes placing oneself in dangerous situations like homelessness, or inability to maintain healthy living conditions or diet. Others have held that a person must be in immediate danger of causing serious physical danger to themselves or to others.

The United Nations Office of the High Commissioner for Human Rights says that every person with a mental illness "shall have the right to exercise all civil, political, economic, social, and cultural rights as recognized by the Universal Declaration of Human Rights, the International Covenant on Economics, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and other international agreements. In any decision that a person, by reason of a psychiatric disorder, lacks capacity to make legal and other important decisions in respect to their life, a personal representative may be appointed, only after a fair hearing by an independent and impartial tribunal established by domestic law." UN General Assembly (1991). This is pretty much in keeping with current mental health laws in most states in the US.

"The person whose capacity is at issue shall be entitled to be represented by counsel. If the person does not secure such representative, it shall be made available without payment by that person to the extent that they do not have sufficient means to pay for it. That counsel shall not in the same proceedings represent a mental health facility or its' personnel and shall not also represent a member of the family of the person unless the tribunal is satisfied that there is no conflict of interest. Decisions regarding counsel and representation shall be reviewed at reasonable intervals prescribed by domestic law. The person whose capacity is at issue shall have the right of appeal to a higher court regarding any ruling made." UN General Assembly (1991)

Just as our legal system works on the presumption that a person is innocent until proven guilty, individuals diagnosed with a psychiatric disorder should not be presumed legally incompetent without due process. We have a long history of taking away the freedom of informed consent with insufficient evidence.

In 1964 the District of Columbia set a standard for civil commitment that established that a person must be determined to have a mental illness before he or she could be hospitalized against his or her will. Second, the person has to pose an imminent threat to them self or others or be proved to be "gravely disabled" meaning

Compassion: "Deep awareness of the suffering of another coupled with the wish to relieve it."

The American Heritage Dictionary of the English Language
(2009)

that they could not provide for basic survival. The statute left room for interpretation, however it is commonly interpreted that dangerousness refers to physical harm to self or others, and that the requirement for imminence means the threat must be likely to occur in the close future. Over time most states adopted similar standards for involuntary commitment. Delaware only requires proof that the person is not able to make "responsible choices" about hospitalization or treatment, while Iowa's law only mandates proof that a person is likely to cause "severe emotional injury" to people who are unable to avoid contact with him or her (e.g. family members). Testa, M., et al (2010)

Sandro Galea, the chairman of epidemiology at Columbia University's Mailman School of Public Health, said that those who suffer from mental health issues are, in fact, far more likely to be victims of violence than perpetrators. Helfand, C. L. (2013) "People with severe mental illness, schizophrenia, bipolar, or psychosis are two and a half times more likely to be attacked, raped, or mugged than the general population." Hiday V. A. (2006)

Galea goes on to say "Our proclivity is to highlight when an individual with mental illness is found to be responsible (for a crime), but the truth is that they are far more likely to suffer". He continued, "The proportion of harm to others that is brought about by people with mental illness is so vanishingly small that it is not a rationalization for mental health reform". Helfand C. L (2013). The MacArthur Violence Risk Assessment report, a large scale study completed in 2001 in the United States showed that the prevalence of violence among those with a major mental disorder who did not abuse substances was indistinguishable from their non-substance abuse neighborhood controls. Monahan J. Steadman H. J. Silver E., et al. (2001). The Treatment Advocacy Center (TAC) quotes studies that show that 10% of homicides are committed by individuals with severe mental illness, but does not state what percentage involve substance abuse. TAC (2014)

Doris Fuller, Executive Director of the Treatment Advocacy Center, says that it is unfortunate that the violence of suicide is not talked about enough. Dangerousness and violence does not just refer to the potential of harm to others. Suicide is the 10th leading cause of death in the US. A serious limitation of clinical explanations of violent and disruptive behavior is their focus on the mental illness and the people with mental illness, to the exclusion of social and contextual factors that interact to produce violence in clinical settings. Even in treatment units with a similar clinical mix and acuity, rates of aggressive behavior are known to differ dramatically, indicating that mental illness is not a sufficient cause for the occurrence of violence. Katz P., Kirkland F. R. (1990)

Studies that have examined the antecedents of aggressive incidents in inpatient treatment units reveal that the majority of incidents have important social/

structural conditions such as ward atmosphere, lack of clinical leadership, overcrowding, ward restrictions, lack of activities, or poorly structured activity transitions. Stuart H. (2003) Katz P., Kirkland F. R. (1990); Shepard M., Lavender T. (1999); Powell G., Caan W., Crowe M. (1994) A Finnish study found that treatment culture may play a role in the application of involuntary measures during a psychiatric inpatient stay. Kaltiala-Heino R., Valimaki M., Korkeila J. (2003) Salize H. J., Dressing H. (2005)

A logical conclusion would be that violence in the community is also dramatically influenced by social/ structural conditions. A vast number of people with severe psychiatric disorders live in poverty and frequently are homeless or live in group settings. How often is violent behavior a reaction to what is going on in a person's life and not a symptom of a psychiatric disorder? Leah Harris, Director of the National Coalition for Mental Health Recovery, believes we need to create conditions where violence is less likely, that end isolation and promotes connectedness.

The public are accustomed to "experiencing" violence among people with psychiatric disorders, although these experiences are mostly vicarious through movies or real life drama played out with disturbing frequency on the nightly news. The global reach of the news ensures that the public will have a steady diet of real-life violence linked to mental illness. Stuart H. (2003). A series of surveys done in Germany showed that the public's desire to maintain social distance from "the mentally ill" increased markedly after each publicized attack, never returning to initial values. This coincides with increases in public perceptions of the dangerousness of people with mental illness. Stuart H. (2003) Angermeyer M. C., Marschinger H. (1995)

States continue to commit individuals to crisis facilities or hospitals for brief periods of time for an assessment of dangerousness, (typically 72 hours, sometimes longer) after which they are entitled to a hearing before a court to determine whether their involuntary commitment should continue based upon the above criteria. At these hearings the individual is entitled to have legal representation present.

In the Supreme Court ruling in *Addington v. Texas*, 1975, the court held that because psychiatry is a field dealing with the inexact science of predicting future risk, the standard used should be "clear and convincing evidence" as opposed to "beyond a reasonable doubt", a lower burden of proof. Several later legal decisions determined that psychiatrists who complete emergency evaluations are required by law to recommend the least restrictive level of treatment that will meet the needs of non-dangerous psychiatric patients. Testa, M., et al (2010)

Some professionals claim that mental disorders almost invariably impair decision making sufficiently that people with such disorders should be considered legally

incompetent.

Conversely, some patient advocates argue that all people with mental disorders are capable of making legally enforceable decisions about treatment and money". Pescosolido, B. A., PhD (1999). It is common for parents to be appointed as representative payees for Social Security benefits, which gives them control of the person's finances. This issue alone is responsible for much of the distrust and ill feelings towards families.

Doris Fuller says that in meetings with a full range of people with a diversity of opinions about treatment there is agreement that the needs of people with untreated psychiatric disorders are not addressed sufficiently. The Treatment Advocacy Center states that, "We focus on the sub-population of people whose brain disorders are the most severe and debilitating because this group is largely under-served by the mental health advocacy community at large and is most likely to benefit from tools like assisted outpatient treatment (AOT)". Doris says that "it is frustrating that compassion and suffering are not driving the conversations".

Overall there is little research into the effectiveness of involuntary treatment considering how frequently it is applied. Mental health care workers need more evidence to support efforts to provide the least possible coercive care with the least possible infringements upon civil rights. Salize H. J., Dressing H. (2005)

In a study on the prediction of readmission of psychiatric inpatients the investigators found that a retrospective analysis of a large U.S. patient file database revealed that involuntary commitments may also have long lasting consequences, as they seem to be significantly associated with a higher rate of readmission. Salize H. J., Dressing H. (2005) Feigon S., Hays J. R. (2003)

Many people, families in particular, hold that standards based on dangerousness force them to watch their loved ones go through progressive stages of psychiatric decompensation before they can get them any help. Further, they argue that the standards of "least restrictive environment or treatment" have led to the fact that 25 percent, or more, of homeless people are individuals with mental disorders, despite the fact that only approximately six percent of the general population lives with a major psychiatric diagnoses. According to Doris Fuller we need a broader view of the cost of untreated mental illness. The question arises though, how much of the homelessness is caused by mental illness and how much is caused by the poverty of living on Social Security Supplemental Income (SSI) and the lack of low cost housing. The waiting list for HUD housing is as high as three years in many states.

It is currently estimated that there is a 10 to 25 percent prevalence of mental illness among people held in corrections facilities, many of whom were convicted of



crimes of survival (e.g. theft of food or trespassing for shelter) related to limited social functioning and inability to meet basic needs due to illness, and poverty. There is significant evidence that people with psychiatric disorders are arrested more often than those without diagnoses that encounter law enforcement under similar circumstances, and people who have been civilly committed have a higher likelihood of arrest than those with a history of voluntary psychiatric hospitalizations. People who have committed felonies and found not guilty by reason of insanity (NGRI) are often hospitalized longer than they would be if they had been found guilty. Testa M., et al (2010)

Programs like Crisis Intervention Team training (CIT), which is a program that trains law enforcement in how to deal with people in a mental health crisis, are highly effective in lowering the rate of injury to the individuals, ensuring the safety of the law enforcement officers, and in reducing the trauma so common to these types of events. The use of CIT reduces the number of arrests of people living with psychiatric disorders, and often prevents the need for involuntary inpatient treatment. In my opinion, we need to move away from using law enforcement to respond to mental health crisis except in the relatively rare cases involving violence. People who are in crisis should not be treated like criminals. Leah Harris points out how far too often police involvement has led to tragedies. In the instances where police involvement is necessary then law enforcement officers should be trained in CIT or other methods of assisting people in a psychiatric crisis.

Safety is another complex concept in the context of mental health. If someone is a danger to themselves

or others, they are not safe. What about when they are homeless, or are using alcohol or other substances to self-medicate? Are they safe when they cannot care for themselves or maintain a healthy diet? And if not, when is the appropriate time to take control of their lives? Scott Bryant-Comstock, CEO of the Children's Mental Health Network, says safety and rights look different when looked at on the age continuum. Families with young children have an obligation to keep their children safe.

For several years I worked for the State of Florida, Substance Abuse and Mental Health (SAMH) program. My boss, Pamela Baker, Ed. D. was the District SAMH Administrator and had worked for many years as a therapist and case manager in Southwest Florida. Pam told me the story of a man she worked with for many years. He had been diagnosed with schizophrenia, then alcohol induced dementia, and finally traumatic brain injury. He was often homeless because he would dismantle the apartments they found for him, thinking he would re-wire them. He rarely bathed and generally smelled terrible, so most residential programs wouldn't take him. He had cancer and had lost half of his tongue so it was difficult to understand him.

He and Pam became friends and the head of SAMH at that time always remembered seeing her with her Gucci purse sitting on a bench talking with this man that most people wouldn't go near. Pam said that he would always take a shower and shave before his radiation treatments because they were important to him. He was very sure about what he did or did not want and often talked about fighting for his freedom. The local community mental health center petitioned for him to be assigned a guardian and Pam went to court and testified in his



behalf that even though he could be difficult he still had the capacity for self-determination. The judge agreed and he lived out his life the way he chose. Pam was asked by his family to speak at his funeral because she was the person who knew him best. Pam taught me a lot about rights and self-determination.

Debbie Plotnick, Senior Director of Policy at Mental Health America cites the abysmal way people frame the issue of safety. It is, far too frequently in the media, only about the safety of others not the safety of the people living with psychiatric distress. People living with mental health issues are far more likely to be victims of violence than they are to be perpetrators, and they are far more likely to harm themselves than someone else.

Forty-five states have passed laws that, in general, say that if someone with a past history of danger to self or others (often including violent acts in inpatient settings), previous involuntary commitments, and is showing symptoms of decline in their mental state they can be court ordered into involuntary outpatient commitment (IOC) or a variation known as Assisted Outpatient Treatment (AOT). While the process had been around for many years, it became a national trend starting in 1999 when a law was passed in New York based on the occurrence of a tragedy in New York City, where a man with untreated schizophrenia shoved a young woman into the path of an oncoming subway train, causing her death. This became known as Kendra's Law, named for the victim, Kendra Webdale.

The decision to invoke IOC is generally made when a person has already been involuntarily detained to assess their degree of dangerousness and found not to meet the criteria for involuntary inpatient treatment. Based upon a medical opinion that they are still in jeopardy of becoming imminently dangerous to self or others, have a history of involuntary commitment, and that they lack insight into the need for treatment, they appear before a court or magistrate who then orders them to submit to involuntary outpatient treatment assuming that it is available. "It is a preventative approach to trying to avoid not only inpatient care but also the much more deleterious outcome of homelessness and incarceration". Sharfstein, S. S., MD (2005). The reasoning behind the passing of these laws was that it would compel the provision of services that had not been available or utilized by the individual. Is this really the best way to improve services?

The Rand Institute for Civil Justice study of the effectiveness of involuntary treatment completed in 2001 concluded that the study did not prove that treatment works better in the presence of coercion or that treatment will not work without coercion. Ridgely, M. (2001) "This use of outpatient commitment is not a substitute for intensive treatment; it requires a substantial commitment of treatment resources to be effective." Swartz, M., et al (1999)

The reality of this type of court order is that the decision has been made that the individual is not competent to make informed consent, so if they continue to refuse treatment they cannot be held responsible for their actions and therefore cannot be held in contempt of court and unless they now meet involuntary inpatient criteria they cannot be held against their will except for the purposes of another evaluation which few states have sufficient space or funding to accommodate. Rather, these laws rely on a phenomenon that Brian Stettin, of the Treatment Advocacy Center, the organization that has helped write many of the IOC laws, refers to as the "black robe effect" which is the sense of authority society ascribes to judges, and so people are more likely to comply with their orders even when there are no legal ramifications for refusal.

The real question is, are the services people need actually available when they need them, and are professionals living up to their responsibility to effectively engage people so that they willingly accept treatment. That may not always be possible but it is far more often possible than it is done.

The basis for laws that allow the state to restrict the freedom of people with psychiatric disorders who are deemed "dangerous" is based in the common law principles of *parens patriae*, a Latin term that means "parent of the country" and is the doctrine that assigns the government responsibility to intervene on behalf of citizens who cannot act in their own best interest, and in the principle of "police power" which requires a state to protect the interests of their citizens. Because of this obligation to all citizens the state is able to enact laws that restrict the liberties of certain individuals.

It is clear that these laws are based on subjective observations and therefore hold the risk of someone being mandated to involuntary treatment that does not actually represent an "imminent risk of danger to self or others", or is not at clear risk of becoming so. In those cases the rights of very real people are being violated. Are we making a good decision when we are willing to sacrifice the rights of some to ensure the safety of others? The standards for involuntary treatment should be high and should be uniformly enforced.

In the criminal justice system a guiding principle is that it is "better that ten guilty men go free than an innocent man be imprisoned". We uphold that principle even in capital crimes, yet in making decisions about a person's rights to accept or refuse treatment, or freedom from involuntary commitment we lower the standard of "beyond a reasonable doubt" to "clear and convincing evidence". As someone who has served as a guardian advocate in involuntary commitment hearings, I can say that the evidence is often less than clear.

Why is the freedom of a person with a psychiatric disorder determined using lower standards of justice

than for an accused criminal? Dan Fisher, MD, PhD, the Executive Director of the National Empowerment Center, believes that there are two legal systems in effect, the civil law system based on due process, habeas corpus, and "beyond reasonable doubt" and the mental health law system that often relies on a single medical opinion. Dan quotes a person he saw as a doctor, while working in a program to divert people from jails to treatment, who said "I'm not covered by the Bill of Rights".

In a statement to United Nations Human Rights Council in Geneva in March 2013, the *U.N. Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment of Punishment* called for a ban on forced psychiatric interventions including forced drugging, shock, psychosurgery, restraint and seclusion, and for repeal of laws that allow compulsory mental health treatment and deprivation of liberty based on disability, including when it is motivated by "protection of the person or others." United Nations Human Rights (2013)

Our enforcement of existing laws for commitment is frequently applied inconsistently. I once had a friend drive me to the emergency room of the hospital where I had been a patient on the psychiatric ward several times. My personal crisis plan and my agreement with my doctor was that when I became aware of my early warning signs that I was heading into a major crisis, I would go to the emergency room and my doctor would arrange for me to be admitted voluntarily. I have bipolar disorder with rapid cycling and I know that my moods can shift very quickly. Upon finding out that my doctor was out of town I explained my plan to the ER physician. I was not dangerous, but I was in crisis.

After 6 hours in the ER I realized that this was only exacerbating my situation and that I would be better off in the security of my own home with the support of friends. When I explained this to the doctor he replied that I would not be allowed to leave and would be involuntarily detained. The assumption was that if a person came in and said they had a major psychiatric disorder and wanted to be hospitalized then they must be a danger to their self or others. Ironically, at that time I was working for the state office of substance abuse and

mental health and one of my responsibilities was helping to train professionals in the proper use of involuntary holds.

Explaining that I did not meet criteria did not get me very far and so I waited patiently under the watchful eye of a guard until a sheriff's deputy came to transport me in handcuffs to a crisis center. The deputy talked to me and was confused about why this was happening. After he walked me out to the car, out of sight of the ER, he released the handcuffs and drove me to the facility where I was released after a brief interview. My rights were violated, either from compassionate caution, or fear of liability. A minor instance, certainly, but highly indicative of predominant attitudes.

Several years before, I had a day where I went from an optimistic morning to a calm, reasoned decision to die by nightfall. I don't remember anything about the paramedics breaking in my door, I just remember waking up 30 hours later in an ICU. My last memory was that I decided that it would be too hurtful not to tell my brother, who lives with the same disorder, why I made this choice. I remember how calm and at peace I was. I wanted to die.

I had just moved to a new apartment and I knew that my brother, who lived 400 miles away, did not know where I lived. I remember telling him I loved him and how this was the right choice, and then there was nothingness. What I hadn't thought about was that my brother would call everyone he could until he found someone who knew where I lived. He did and somehow the paramedics arrived just after I lapsed into unconsciousness. And so I awoke after 30 hours in an ICU with the taste of charcoal in my mouth and complete confusion. I was held under involuntary status for four days. At first I was angry that I had lived, my brother had gone against my wishes and saved my life. Within hours I saw the world in a completely different way. I was glad my brother had intervened. I have the rapid cycling type of bipolar disorder and have often cycled from hour to hour.

I do believe in the right to die. When life becomes intolerable everyone should have the right to decide to

"To cheapen the lives of any group of men, cheapens the lives of all men, even our own. This is a law of human psychology, or human nature. And it will not be repealed by our wishes, nor will it be merciful to our blindness."

- William Pickens

leave it. The tragedy is when the driving force for wanting to die is transitory, and there is a chance for a better life. I saw an anonymous quote once that said "Don't make a permanent decision for your temporary emotion." So, had my rights been taken away in the name of compassion? Maybe, but at least it was done legally. I met the criteria of imminent danger to self or others due to mental illness. I admit that I'm glad I'm alive, and I agree that there are times when I and many others are at risk. Dan Fisher, an ardent advocate for the abolition of forced treatment says that currently there are still instances where we don't have sufficient alternatives to reach everyone voluntarily but that this should be our goal.

Doris Fuller agrees that we do not have the ability to keep all people out of severe crisis and she believes that we probably never will. She says the line is different for everyone when it comes to involuntary treatment. People have a right to treatment before crisis.

Physicians' professional responsibilities are based on ethical principles of medical practice dating back to the time of Hippocrates. "The first and foremost principle of medical ethics is that of non-maleficence, the physician's duty to 'do no harm'. One way that physicians can avoid harming patients is by showing respect for their autonomy (i.e., by allowing patients to make their own decisions regarding whether to accept or reject recommended medical care). Physicians are also bound by a professional obligation to help patients. This duty is prescribed by the ethical principle of beneficence, which requires that doctors provide to patients services that will benefit them." Testa, M., MD et al (2010). For many physicians this can cause an ethical dilemma.

In recent years research has taught us that much of what we call "mental illness" is due to trauma. What about the question of the trauma we inflict when we involuntarily treat someone, when we medicate them against their will? What happens when we physically or chemically restrain someone, or we place them in seclusion? People are less likely to participate in treatment, they move further away from the world around them and react to external stimuli in unpredictable ways, perhaps even violently if it fits the construct in which they live. Are these things not traumatizing? It seems we need more compassionate methods of treatment.

Leah Harris says that if we look at psychiatric disorders through the lens of trauma it fosters compassion in our reaction to crises, and opens our idea of safety to include the harm that may occur in the name of treatment. She believes we must build a system that is sensitive to trauma and understand that these issues are not purely medical. It is important when a person is in crisis that we find out what is going on, and that we ask the individual that question.

Psychiatrists often encounter cases in which patients are in grave need of treatment yet refuse to cooperate

with the provision of the necessary treatment. In these cases, psychiatrists face the challenge of weighing their professional obligations of "do no harm" and beneficence in deciding whether to hospitalize patients against their wishes. Testa, M. MD, et al (2010). This is a growing topic of debate within the medical community, not only regarding mental health issues, but in the greater context of end of life decisions. When an individual is suffering from a severe mental illness that grossly distorts his/her perception of reality, it is often clear that he or she has lost the usual capacity for making decisions in his or her best interest, but does this constitute the legal basis for rescinding their right to refuse treatment. Fortunately, many states have drafted psychiatric advance directives, legal documents that people fill out when they are doing well and are competent under the law to make decisions. In these directives individuals can say how they wish to be treated when they are declared incompetent. Greater use of advance directives and adherence to them by medical professionals would solve many of the problems of involuntary treatment.

Different doctors seeing the same person frequently have diametrically opposed opinions about their state of mind. Our system for diagnosis, The Diagnostic Statistical Manual 5 (DSM 5) is so unreliable that The National Institute of Mental Health no longer supports it, with Director Thomas Insel stating that the reason "is its' lack of validity" Lane C. (2013) That puts into question our whole legal concept of mental illness and creates another barrier to a process based on science to provide involuntary treatment. Our previous experiences with institutionalization and human rights violations should be a powerful warning of caution as we broaden the standards we use to remove rights in the name of compassion and safety.

In looking at the public's willingness to use legal means to force individuals into treatment there is clear discrimination by type of mental health problem. 49.1% of people surveyed in a study in 1999 felt that there was a need for coercion to get people to visit a clinic or doctor for people with schizophrenia as compared to 21.6% for people with major depression. 42.1% believed there was a need to use coercion to get people with schizophrenia to take prescription medicine versus 24.3% for those with major depression. 12.8% felt that a person with schizophrenia was very likely to do violence to others and 48.1% felt they were somewhat likely, despite the fact that the incidence is very low. For major depression 9.2% felt very likely and 24.1% felt somewhat likely. Pescosolido, B. A., PhD (1999). The most likely form of violence perpetrated by either group is suicide and the incidence of violence to others is very small. National Institute of Mental Health (2014)

Dan Fisher believes that this improper linkage of psychiatric diagnoses to violence drives us away from compassion and rights. He says "Fear blocks compassion and human rights", and he wonders why we are such

a frightened society. Dan believes the current wave of fear of “mentally ill” people with guns is the same phenomenon as the overreaction to the danger facing the American community from Ebola.

He believes the fear is being driven by a breakdown of community as people become islands unto themselves and are separated from others by technology. In developing countries people notice each other more and are never alone. For all of the positives technology has brought to the world it has an effect of separating us.

“Nobody denies that people can become very overwhelmed with life, and experience extreme states of mind or exhibit problematic thoughts, feelings and behaviors.” MindFreedom (2014) Forced psychiatry is controversial because it imposes a choice made by others on the individual who is going through a crisis. This represents government forcing its interpretation of the person’s problems on them, and forcibly altering that person’s body against their will. “Forced psychiatry represents the ripping away of choice in what treatment a person may want, what interpretation of their problems they may have, and what solutions that person may seek to their problems. Reaching out for help from the mental health system often comes at the cost of your basic rights, and many live in constant fear of being assaulted by the coercive and violent procedures that are central to modern forced psychiatry.” MindFreedom (2014)

So, what of the argument for compassion? Is it still compassion when exercised through coercion? Do we set aside the rule of law, and human rights to protect those we love? How do we know we are right, are we willing to give up the freedom of millions based upon inexact science, unreliable statistics and laws with lower standards for incarcerating people with psychiatric disorder than for criminals? Sometimes families, loved ones, and even providers are so worried about the outcomes for a person that they are willing to set aside rights in the name of compassion. What about when we are wrong, when our loved ones are sick and vulnerable but not dangerous? If in those times we force them into treatment, detain them against their will, restrain and seclude them, is it possible that we do more harm than good? There are no easy answers.

This brings up the question of why do we treat people in psychiatric distress the way we treat criminals? Why do most people in crisis get transported to the hospital or crisis unit in handcuffs in a police car? Criminals in need of medical care are at least transported in ambulances, even if they have to be handcuffed. Why do some mental health facilities still use draconian seclusion and restraints when other facilities have found far more compassionate alternatives? Why do we heap humiliation and trauma on people who are already on the verge of total despair.

After much reflection I go back to the guiding principle I have followed in all my years as an advocate, “it all

begins with rights”, but that also means it begins with compassion. “Related to rights is the issue of respect and dignity. Compassion... is sensitive to, respectful of, and boosting of dignity”. Gilbert P., ed. (2005). Our laws must be clear, they must be founded in rights, and they must be adhered to. Treatment is not the only expression of compassion, upholding human rights is truly compassionate. When society decides it is necessary to limit those rights, it must be done in law, and it must be clearly reasoned.

There is a current statement in the movement to strengthen IOC; it is that rights advocates are willing to let people “die with their rights on”. It is a ridiculous statement, only intended to divide us. Many of us are the ones whose lives have been in jeopardy. We are not against protecting people’s lives, rather we support protecting their lives and their rights. Families and loved ones will make their decisions as they will, but society must live by the founding principles that have ensured freedom and greatly limited restrictions of rights for all. When we strip away one man’s rights without cause we endanger the rights of all, and we succumb to the principle that the end justifies the means.

Do I believe in involuntary outpatient commitment? Not really, I believe that our efforts are far better spent in building a better, more comprehensive system of care that does a far better job of early engagement, particularly for people who may not initially want assistance. The mental health profession can do a much better job of engaging people in services and supports that help them than we currently do, we need more effective outreach. I have had the opportunity to work with people who are very good at engaging people into services, even those who do not initially believe they need or want them, so why don’t we do that more often?

I believe that far more effort should be put into keeping people well than into waiting to provide crisis services. Currently, in many places in this country our priorities are completely backwards. Often, help is not available when it is needed and for many this results in arrest and jail. More people receive their first mental health treatment in jail or prison than in the public mental health system.

Then, there is the subject of mental health care being withdrawn or withheld for financial reasons. What does it say about a society that allows insurance companies to force people out of inpatient care when they really need it, because they are not willing to continue to pay for it? Payers limit the provision of needed medical assistance and often force doctors to go against their own medical opinions. What are the consequences? People end up in deeper crises and cycle right back in with worse outcomes. As strange as it might sound, people have a right to treatment, even involuntarily.

It is actually easier to understand that funders of mental health services are not always driven by compassion

than it is to understand how they think that cutting front end services doesn't end up costing society far more when people end up in ER's, crisis units, hospitals, jails and prisons, and on long term disability, no longer contributing financially to the community. These conditions are neither compassionate, safe, nor upholding of human rights.

What of the concept of compassion in the greater sense, in the way that western society avoids and marginalizes people with psychiatric disorders. When you consider the prevalence of mental health problems in the world and how many families are touched by them, it is incredible how much we push the people living with these conditions to the fringes of society.

My friend, Gordon Dean, a parent of a grown child with schizophrenia, and a powerful family advocate believes that our societal aversion to what we call mental illness is, somewhat, rooted in religious beliefs, and the rest in the misguided idea that mental illness is closely associated with violence. Gordon also points out that families are the subject of stigma; families with a loved one with a psychiatric disorder rarely invite people over. Doris Fuller says that one thing that concerns us all is stigma. It arises, largely, from the attention given to a relatively few random incidents of violence involving people with psychiatric disorders. Leah Harris says there is a conflict in society in that our heightened fear of dangerousness infringes on the rights of the individual.

Stigma probably isn't the best word to use, in most dictionaries the primary definition is *"a mark of disgrace or infamy; a stain or reproach, as on one's reputation"*, though the Merriam Webster Dictionary also defines it as *"a set of negative and often unfair beliefs that a society or group of people have about something"*. I think more appropriate words are prejudice and discrimination. With the word stigma it is too easy to believe that it something that

is wrong with the individual and not with the person who imposes it. This is another example of the need for compassion.

Debbie Plotnick says that there is an old belief that vulnerable people need to be helped even if they don't want it. Dan Fisher says there is something wrong with our model of help, we take people's rights away to help them, and our pattern of thought is that people are broken machinery that needs to be fixed.

Kai LeMasson, PhD, at the Florida Mental Health Institute at the University of South Florida says that even if they are well intentioned, a family member's or loved one's understanding of what is going on with a person in psychiatric crisis may be shaped by social and cultural forces that may be highly skewed. She says that "compassion in treatment begins with recognition that a person is suffering" and sometimes recognition that the family is suffering as well.

I suppose, in large part, this is due to just how disruptive and difficult it can be for families and friends. Many of us with lived experience with psychiatric disorders begin to distrust those closest to us, in part because they often try to push us into services that we find scary and even harmful. Sometimes "normal" people are afraid of others who are different, and they have a deeply rooted idea that we are far more dangerous than what is born out in fact.

Another factor is that the costs of care for people living with severe debilitating disorders are so high that families and loved ones cannot afford to continue to provide for them. This pushes people into public assistance, and in a society that is increasingly reluctant to provide for even the basic needs of the most vulnerable of those among us, that means living at the lowest rung of the economic ladder. We, as a society, don't like to look too closely at



"The rights of every man are diminished when the rights of one man are threatened."
- John F. Kennedy

poverty, we don't like to be around people dressed in second hand or cheap clothes, who live in shelters, group homes, tenements, or are homeless on the streets.

That doesn't mean that many families, friends, and loved ones don't feel compassion. Sometimes we find that the only way people can get the medical assistance they need is by cutting them loose financially so that they can qualify for Medicaid. Sometimes it is the only way the family can survive, and sometimes, too many times, it is because people experience "compassion burnout" from years of living with the pain and suffering of watching a loved one and a family descend into chaos.

We have to remember that parents make decisions for the whole family not just the member of the family who is ill. There are so many factors to take into consideration when deciding how a family is going to respond to a psychiatric crisis. Parents must consider all of their children, and the stability of the family. Families often feel that they have to involve a reluctant system to get assistance for their loved one. When faced by situations that may endanger members of their families or the family unit they are often desperate for a solution even when it involves forcing their loved one into involuntary treatment.

The facts are that people with psychiatric disorders are marginalized, they are forced into poverty by their disability, and they receive substandard services. We don't provide them with what we know works, with evidence based practices, instead, we concentrate our resources on crisis services. We don't use effective means of engagement for people who don't want services or who don't believe they need them. Sometimes, with patience, people who do need assistance will engage when approached in a compassionate manner. We wait to engage them involuntarily. We don't educate enough young professionals in the concepts of recovery and compassionate engagement.

Compassion, safety, and rights are closely related, often in tandem, often in conflict. They are three of the most important issues in mental health. In the end, for me, upholding our rights is the most clear expression of compassion and the moral path towards the safety of society, which is not always in line with each individual's ideas of the safety. Consequently, we will always see individuals making decisions that violate the rights of their loved ones because of their fear for their safety. This can only be solved by building a better, more effective, more compassionate system of care.

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