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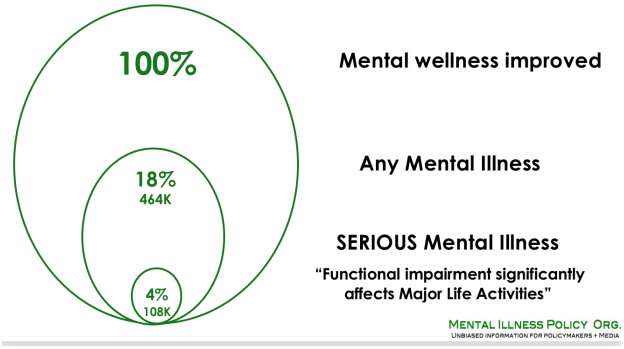
Testimony of DJ Jaffe, Executive Director, Mental Illness Policy Org
as prepared for presentation to
Utah Health and Human Services Interim Committee
July 18, 1018

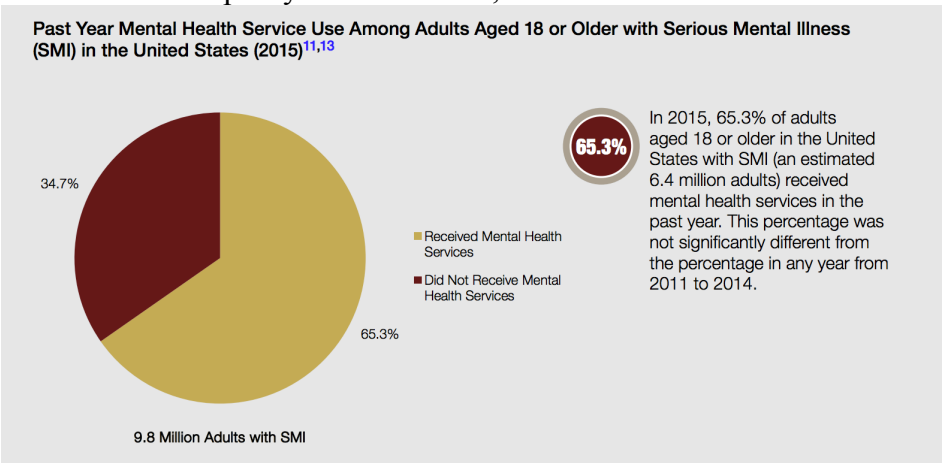
My name is DJ Jaffe, I am executive director of Mental Illness Policy Org., a non-partisan, non-profit founded and funded by families of the seriously mentally ill to improve mental illness policies. I have a seriously mentally ill relative and am the author of "Insane Consequences: How the Mental Health Industry Fails the Mentally Ill."

I thank Senator Fillmore, Representative Daw and the committee for inviting me. That is not just a pro-forma statement. We are not always invited to mental health committee meetings because unlike NAMI, MHA and others we are not mental health advocates. We are advocates for the most seriously mentally ill.

To put that in perspective 100% of the adult population can have their mental wellness improved, 18% have something in DSM, often mild things, but only 4-5% of adults have serious mental illness, meaning they have a functional impairment so serious it affects their ability to engage in major life activities[1], [2] That means in Utah 464,000 adults have mental illness, but only 108,000 have serious mental illness.



The most important statistic is that if national averages apply here, 35% of the Utahans with *serious* mental illness did not receive treatment this past year. [3] That's 38,000 adults.



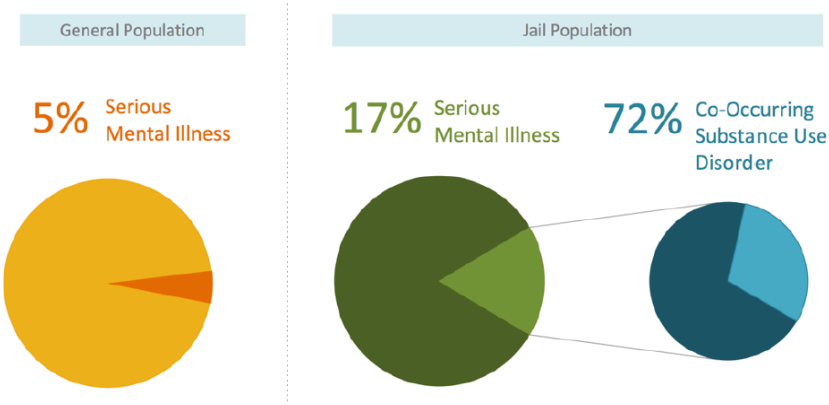
That should be the elephant in the room—delivering treatment to the 38,000 Utahans with serious mental illnesses like schizophrenia and bipolar who receive zero treatment. They are the ones most likely to become homeless, arrested, violent, incarcerated, and needlessly hospitalized.

"We spend way too much on mental health and not enough on serious mental illness."

Based on my research around the country, which I assume--but do not know--holds true for Utah, the most important message I can give you is that as a result of advocacy by the mental health community, legislators allocate way too much to mental health and not enough to serious mental illness. The ability to get care throughout the country has become inversely related to need. The least seriously ill go to the head of the line and the most seriously ill go to jails, shelters, prisons and morgues.

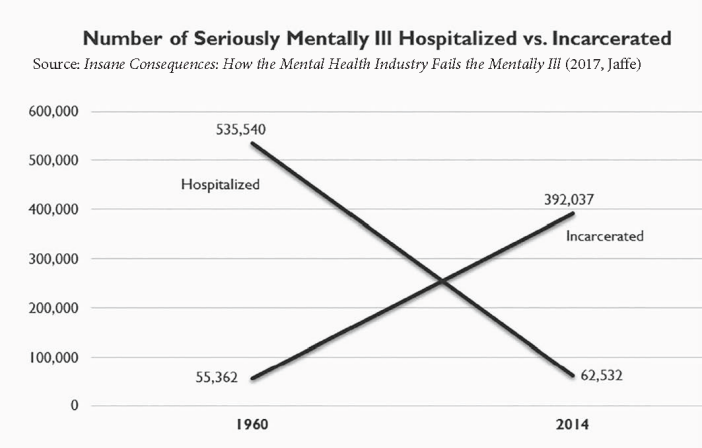
The focus of mental health departments has largely turned to helping people who feel sad, anxious, lost a loved one, experienced misfortune, received a bad grade, were bullied, had something they perceived as traumatic happen, are going through divorce, are under pressure at work or have other issues the mental health industry has decided are risk factors or mental health conditions. They are wrapping worthy social services for these populations in a mental health narrative and diverting resources to them. Nothing's left for the seriously ill.

The seriously mentally ill are being offloaded to criminal justice. I am here in Park City speaking to judges at the National Mental Health Court Summit because they are very concerned about this phenomenon. I hope the mental health department is concerned as well.



Look what's happened, we used to have a hospital based system which by definition served the seriously and have now moved to a community based system that is not treating those so seriously ill they would otherwise go to hospitals. So they are going to jails which are now opening hospitals. The fact that we closed beds at Utah State Hospital and are opening competency and forensic beds is an example of this.

The data is very clear: as hospitals go down, incarceration goes up.



If you look at number of people in psychiatric hospitals and incarceration in 1960 and compare it to today, in 1960 the vast majority of institutionalized were in hospitals and today the vast majority of institutionalized are behind bars. The total institutionalized is largely the same with homelessness accounting for the difference.[4] But institutionalization moved from hospitals to jails.

Preserving psychiatric hospital capacity and even expanding it has to be a key part of any plan to improve care, but you won't likely hear that proposed by the mental health advocates who after all, run community, not inpatient programs.

Meet with criminal justice. They are the experts.

So I encourage you to meet with criminal justice. Ask sheriffs, corrections, district attorneys, police, and judges "How can we stop the mental illness to jail pipeline?" Criminal justice officials are now the real experts on serious mental illness. If only 15% of the inmates in Utah State Prison and Salt Lake County Jail have serious mental illness, then the jail and prison are Utah's two largest mental hospitals. Utah State Hospital is third with 324 patients.

Take the issue of violence. If you meet with mental health advocates they will claim the mentally ill are no more violent than others. Criminal justice folks will tell you that's simply not true for the untreated seriously ill. If people with untreated serious mental illness really are no more violent than others than the mental health community should explain why psychiatric units are locked and liver units are not. Why psych nurses wear panic buttons and those in heart units do not. Why do mental health outreach workers go out in pairs for their own safety?

If you meet privately with criminal justice, without mental health experts in the room, they can be honest, rather than politically correct and you may be surprised by what they say.[5]

I am going to describe two ways to stop the mental illness to jail pipeline. I'm going to talk about civil commitment reform and HIPAA, but first I want to make a global suggestion.

Recommendation: Focus the mental health department on improving meaningful metrics in seriously mentally ill

The department's mission as stated in the annual report is exceedingly vague and unfocused. It calls for "promot[ing] hope, health and healing."[6] Neither the mission, nor the five state strategies focus on reducing rates of homelessness, arrest, incarceration, violence and needless hospitalization of the seriously mentally ill. That should be the primary mission. You should require the mental health division to measure those rates annually and report on them.

Instead, the Utah Department of Substance Abuse and Mental Health Services measures the number of people served and 'customer satisfaction," much less useful metrics than the metrics I cited.[7] Number of people served says nothing about how many seriously mentally ill are served. Customer satisfaction among those being served fails to recognize 38,000 of the most seriously mentally ill are going unserved.

Recommendation: To reduce homelessness, arrest, incarceration and the other important metrics focus on those most likely to experience them. **Pass legislation mandating evaluation of all seriously mentally ill who are being released from involuntarily commitment or incarceration.** Those are the two groups most likely to recidivate and become a problem. They have a prior history. Evaluate them and connect them to services, including assisted outpatient treatment if needed.

Recommendation: Don't be beguiled by the term 'evidence-based' or the number of programs that claim to be evidence based. If someone says a program is 'evidence-based' ask "evidence-based to do what to who and is

the evidence independent?" To be evidence based a program should meet three criteria. It should 1) have independent evidence it 2) improves a meaningful metric in 3) the target population, the seriously mentally ill. Meaningful metrics include rates of homelessness, arrest, incarceration, violence, needless hospitalization and suicide.[8] Utah Division of Mental Health is funding many non-evidence based programs and claiming they are evidence based. These include Mental Health First Aid to reduce suicide,[9] Wellness Recovery Action Plans (WRAP),[10] peer-support,[11] prevention programs[12] and others.

Be wary of programs that promise prevention. Mental health advocates claim "if we intervene early, we can *prevent* mental illness." But schizophrenia and bipolar disorder which make up the majority of the 4% with serious mental illness can not be predicted or prevented. There will be a Noble Prize for whoever figures it out.

Turning to civil commitment reforms.

Civil commitment reforms

Being psychotic is not a right to be protected it is an illness to be treated. John Hinkley shot Ronald Reagan because he knew that was the best way to get a date with Jodi Foster. That is not an act of free will, that is a free-will that has been hijacked by illness. Medications can restore free will and enable people to engage in a meaningful exercise of free will.

We can't simply abandon people because they are too psychotic to recognize they are ill.

Roughly 40% of people with serious mental illness are so sick they don't know they are sick. It's called anosognosia. The brain, the organ charged with insight is the one that's damaged. When you see someone walking down the street screaming they are the Messiah it is not because they think they are the Messiah. They know it! Their illness tells them it is so. They don't want treatment for their Messiah-hood, they want it recognized. The criminal justice system is spending massive amounts of money restoring the competency of these individuals after they become criminally involved, only because the mental health system wouldn't do it before.

We place people like this in terrible Catch-22s. If you are well enough to voluntarily walk into a psychiatric emergency room, the bed shortage is so severe, you are considered not sick enough to be admitted. And if you are not well enough to recognize you are sick, you can't be admitted over objection until after you become dangerous. That's ludicrous. Laws should prevent violence, not require it. Following are some civil commitment reforms to consider.

- **Pass legislation specifically allowing judges to consider past history when making civil commitment decisions.** Past history is often a sound way to anticipate the future course of illness. A person who deteriorated and became homeless and dangerous off treatment in the past is likely to become homeless and dangerous if he or she again goes off treatment. California recently amended its civil commitment law to allow consideration of past history.[13] Utah should do the same.
- **Pass legislation codifying a need for treatment standard.** The need for treatment standard permits the commitment of an individual who, "due to mental illness, is unable to understand the advantages, disadvantages, or alternatives to a particular treatment or is unable or unwilling to apply them to his or her situation and requires such treatment to prevent severe mental, emotional, or physical harm." It allows treatment before tragedy rather than requiring a tragedy to access treatment.
- **Devote resources to expanding the use of Assisted Outpatient Treatment (AOT).** Outpatient Commitment is for a small group of the most seriously mentally ill who refuse voluntary treatment and needlessly deteriorate as a result. It allows judges to order them to accept treatment while they continue to live in the community. It's less expensive and less restrictive than the alternatives: inpatient commitment or incarceration. It's been shown to lower rates of homelessness, arrest, incarceration, violence and hospitalization in the 70% range in every state where it has been tried and measured while saving taxpayers 50% of the cost of care.[14] I know of no other intervention that is as successful for the

most seriously ill. Legislation I was intimately involved in, led to SAMHSA giving out AOT grants and I know Davis Behavioral Health and Weber Human Services Utah got $750,000 of it.[15]

HIPAA

Turning to family. I will never forget that when my own family member was diagnosed with schizophrenia, my wife and I were not allowed to be told the diagnosis, what medications she was on and what rehab programs she was to attend. As a result we couldn't get prescriptions filled or arrange transportation to programs. She deteriorated again and became an expense to the community. Family involvement improves outcomes. Families that provide case management, housing, clothing, and transportation out of love should be able to get the same information that those who provide those services for money receive.

- **Pass legislation to make signing of HIPAA releases a standard part of admission and discharge procedures for both inpatient and outpatient programs.** Support legislation to give every patient admitted to hospitals and community programs a HIPAA release form as part of the admission process. Write in big letter across the top "YOU HAVE A RIGHT TO SIGN THIS." Make it part of the discharge process too. Make signing HIPAA releases routine so families can help seriously mentally ill relatives.
- **Pass legislation requiring inpatient and outpatient facilities to post signs highlighting patients right to sign HIPAA forms.** Many facilities discourage or fail to highlight that patients have a right to sign HIPAA forms to share information. Signs in facilities can get the information to patients at the time it's needed.

There are many other ideas to improve care for the seriously ill in my book and on our website. Thank you for your time. If you focus on the seriously ill, listen to criminal justice, empower families with HIPAA releases, supplement existing civil commitment laws, and task the mental health department with reducing rates of homelessness, arrest incarceration suicide and needless hospitalization, we can save money and start to close the spigot that is flooding the criminal justice system with untreated seriously mentally ill.

Thank you very much for your concern about these issues. I'd be glad to answer any questions you have.

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[1] Among the 44.7 million adults with any mental illness in the past year, 19.2 million (43%) received mental health services in the past year and 57% did not. About 6.7 million of the 10.4 million adults with past year serious mental illness (65%) received mental health services in the past year and 35% did not. https://www.samhsa.gov/data/sites/default/files/NSDUH-DR-FFR2-2016/NSDUH-DR-FFR2-2016.htm. Utah actually has a higher percentage with serious mental illness (5.17%). However, I do not think the measuring tools are that accurate that this should be considered a meaningful or actionable difference.

[2] 2015-2016 National Surveys on Drug Use and Health, SAMHSA, 2017.
https://www.samhsa.gov/data/sites/default/files/NSDUHsaeTotal2016/NSDUHsaeTotals2016.pdf. Tables 26 and 27

[3] https://www.samhsa.gov/data/sites/default/files/NSDUHsaeTotal2016/NSDUHsaeTotals2016.pdf. Table 28.

[4] Jaffe, DJ "Insane Consequences: How the Mental Health Industry Fails the Mentally Ill, Prometheus Books, 2017.

[5] This revelation that criminal justice, not mental health folks are the experts, became apparent to me when I spoke at back-to-back at a mental health industry conference and a criminal justice conference. When I asked how to stop the mental illness to jail pipeline, folks at the criminal justice conference, said we need more hospital beds so when police take someone to the hospital they are admitted, we need easier to meet civil commitment criteria, so we can treat people, we need the hospital to hold longer and stabilize before releasing, make sure they are connected to housing, clubhouses, and other services and are connected to assisted outpatient treatment if they have a history of not staying in treatment.

When I asked the same question at the mental health conference respondents said we have to eliminate stigma, educate the public and we need more peer support. The criminal justice solutions were spot on and would help reduce homelessness, arrest, incarceration and violence. The mental health solutions were politically correct, but largely irrelevant to that goal.

[6] Utah Division of Substance Abuse and Mental Health, Annual Report, 2016
https://drive.google.com/file/d/16ND2aCiFpB3vNor1hB5pqwx9u6gW95kl/view (accessed 7/5/2018)

[7] "Number of people served" fails to account for the severity of illness among those being served, and in fact, encourages programs to serve less ill people so they can claim their total number of people served is going up.

"Customer Satisfaction" data among those in programs fails to recognize 38,000 of the most seriously mentally ill are not in programs. Programs do their own studies so every program in Utah is reporting high customer satisfaction while 35% of he seriously mentally in Utah go unserved. If the department is going to report "customer satisfaction" it should measure everyone, not just those getting services and analyze the data by diagnosis to see if the seriously ill are satisfied.

[8] But many mental health departments declare suicide efforts a success based on number of calls to a helpline, not number of suicides; declare outreach programs a success based on how many contacts were made, not on whether anyone got treatment; declare public

education programs a success based on whether those trained feel educated, not on whether any mentally ill actually got treatment. They also tend to place great weight on meaningless metrics like 'sense of recovery,' 'self-esteem', etc. which can go up, even when the person is incarcerated.

[9] The 2016 annual report of Utah Substance Abuse and Mental Health Division cites Mental Health First Aid (MHFA) as an evidence-based suicide reduction intervention. It is not. (Mental Illness Policy Org., "Mental Health First Aid is Unproven Yet SAMHSA Subsidized," *Mental Illness Policy Org.*, 2013, http://mentalillnesspolicy.org/samhsa/mental-health-first-aid-fails.html (accessed July 12, 2016).)

This is a great example of misusing the term 'evidence-based' and the failure to use meaningful metrics. The meaningful metric when evaluating a suicide program should be number of suicides. Instead, the Utah Mental Health Division measures "change in participant's knowledge, understanding and confidence surrounding the skills presented in the training." MHFA may accomplish that, but there is no evidence it reduces suicide. There is only evidence trained and trainers like it (and even that research comes from the vendor). Surely that should not be enough to have it qualify as an evidence based program.

[10] "WRAP is certified as evidence-based, but is it?" Mental Illness Policy Org. https://mentalillnesspolicy.org/samhsa/wrapunproven.html

[11] "Jury is Out on Paid Peer Support for People with Mental Illness" DJ Jaffe, Psychiatric Times, February 14, 2018. http://www.psychiatrictimes.com/blogs/jury-out-paid-peer-support-people-mental-illness (accessed 7/5/18)

[12] The Department's 2016 annual report cites the Institute of Medicine in support of prevention. IOM does support prevention for substance abuse and some mental health conditions but not serious mental illness which can not be prevented. As far back as 1994, the Institute of Medicine (IOM) exposed the fact that "the nation is spending billions of dollars on [prevention] programs whose effectiveness is not known." (Institute of Medicine (IOM), *Reducing Risk for Mental Disorders: Frontiers for Preventative Intervention Research*, Patricia Beezley Mrazek and Robert J. Haggerty (eds.) (Washington, DC: National Acadamy of Sciences, 1994) http://www.nap.edu/catalog.php?record_id=2139 (accessed July 10, 2016)) In 2014, evidence that preventing serious mental illness is not yet possible was described in an IOM report on efforts to prevent mental illness in the military. (IOM, *Preventing Psychological Disorders in Service Members and Their Families: An Assessment of Programs*, Laura Aiuppa Denning, Marc Meisnere, and Kenneth E. Warner (eds.) (Washington, DC: National Academies Press, 2014), http://www.nationalacademies.org/hmd/Reports/2014/Preventing-Psychological-Disorders-in-Service-Members-and-Their-Families.aspx (accessed July 10, 2016).) The *Wall Street Journal* headline summed up the findings: "Study Fails to Find Evidence That Programs for Soldiers and Families Prevent Psychological Disorders." (Shirley S. Wang, "Military's Mental-Health Efforts are Ineffective, Report Finds: Study Fails to Find Evidence That Programs for Soldiers and Families Prevent Psychological)

[13] The language for this is in California Assembly Bill 1194, October 7, 2015, Chaptered 5150.05 Welfare and Institutions Code, http://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=WIC&sectionNum=5150.05. (accessed August 3, 2016)

[14] Collection of AOT studies is at https://mentalillnesspolicy.org/national-studies/all-studies-on-assisted-outpatient-treatment-aot-in-multiple-states-and-in-counties-of-different-size-show-it-works-pdf.html

[15] Those AOT programs will focus adults with serious mental illness who are on civil commitment, with poor treatment compliance, and a history of multiple hospitalizations and/or incarcerations. They are the most seriously ill. What if there are no services available? Well in that case, AOT does exactly what the mental health system should do: it requires it to prioritize the most seriously ill.

(July 12, 2018)