

Why Voice Matters



Texas Judicial Summit on Mental Health

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In 1976, People with Mental Illness Had Few Rights

In Virginia, nearly 8,000 people were sterilized between 1924 and 1979. About half were deemed “mentally ill,” while the other half were called “mentally deficient.”

Justice Oliver Wendell Holmes: “It is better for all the world if, instead of waiting to execute degenerate offspring for crime or to let them starve for the imbecility, society can prevent those who are manifestly unfit from continuing their kind...**three generations of imbeciles are enough.**”

Because of mental illness, in many states you could not vote, marry, sign contracts, or dispose of property.

Why Listen to the Family? They Caused the Illness...

Double Bind Theory (Bateson, 1956)

- Schizophrenia is a consequence of abnormal patterns in family communication
 - The patient is a 'symptom' of a family-wide problem
 - They become 'ill' to protect the stability of the family system

Treatment Mostly Occurred in State Hospitals

560,000/1.2 million

In 1964, Washington, DC, instituted 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.



What is Tardive Dyskinesia?

Tardive dyskinesia is a neurological condition and a type of dyskinesia characterized by involuntary repetitive muscle movements.

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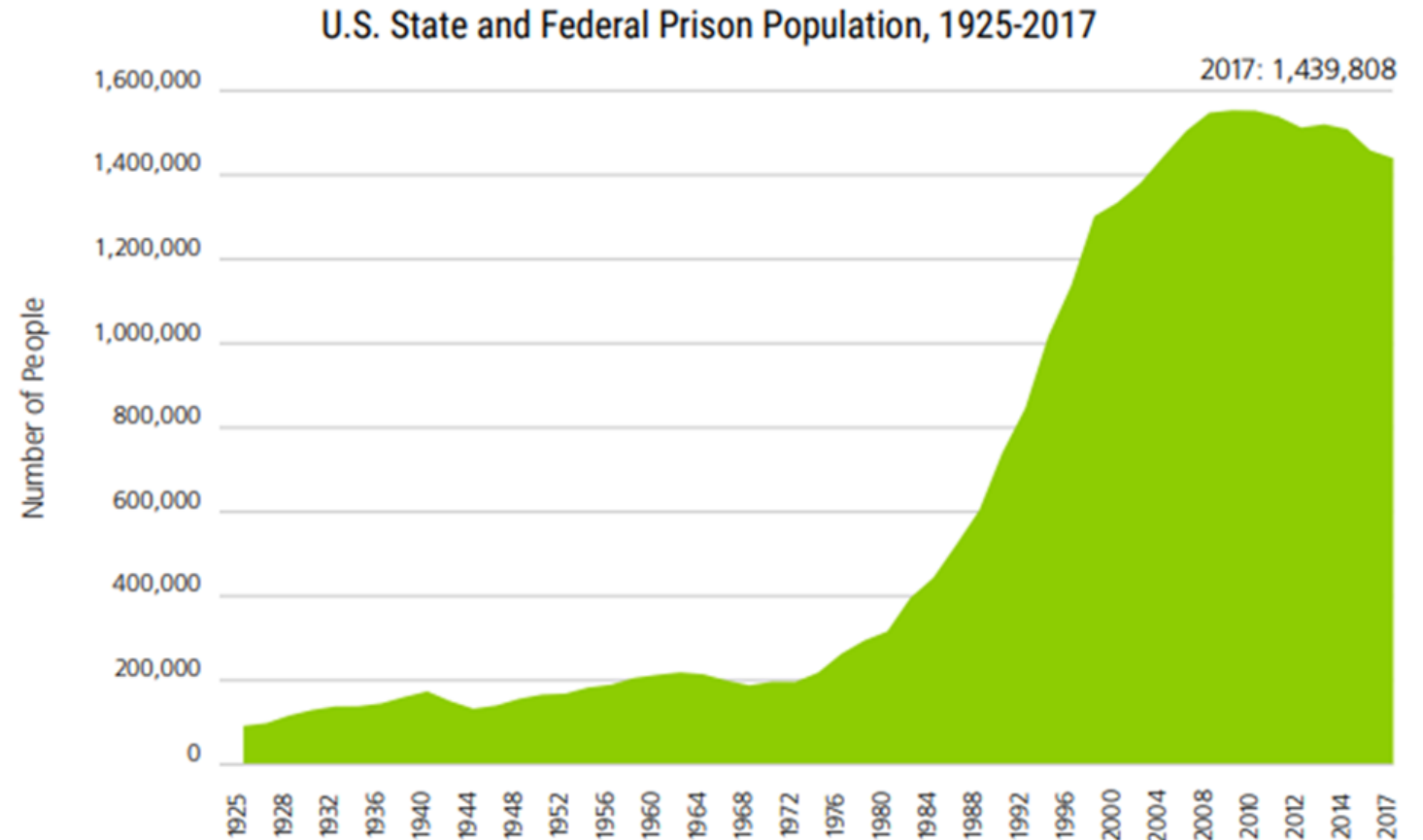
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We Knew Very Little About Treatment and Coercion Was Routine

The Role of Judges Was Constrained

- Competency to stand trial was primarily an issue in felony cases
- Insanity defenses rare
- No adult therapeutic courts
- Juvenile court was rehabilitative

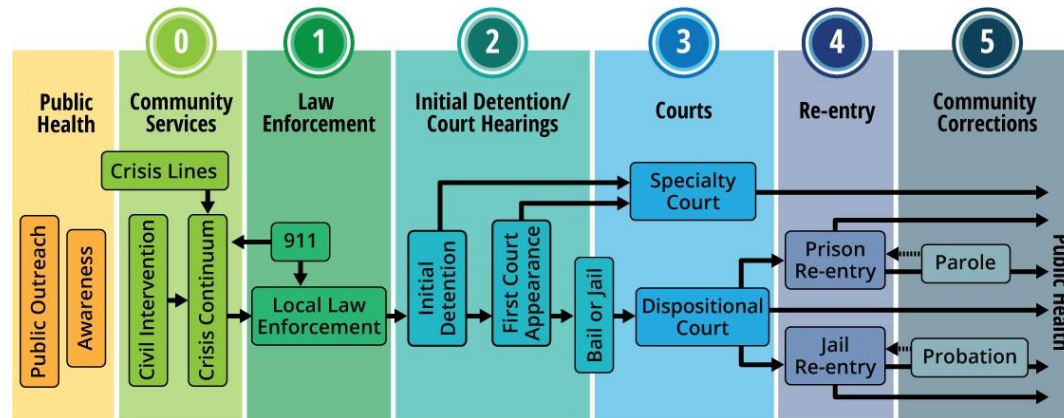


Source: Bureau of Justice Statistics *Prisoners Series*.

The World Has Changed, But Not Enough...

Giving voice to those with lived experience is more important than ever...

JCMH Critical Points Survey and Round Table



- Survey
 - 48 Questions Completed by 13 Individuals with Lived Experience
 - Responses Organized by Intercept and Combined with Best Practices into a Report
- Round Table
 - 30 Participants
 - Input Gathered by Intercept
 - Top 10 Takeaways

Critical Points along the SIM Informed by Lived Experience

1. **Early and accurate diagnosis and intervention improve lives.**
 - *“Had I gotten the earlier diagnosis, I could have addressed the issue instead of cycling in and out of penal institutions.”*
 - *One participant said it would have helped to have been referred to NAMI (or given a brochure with resources) by the pediatrician, teachers, police officers, or the hospital.*

Critical Points along the SIM Informed by Lived Experience

2. Peer support programs are helpful at every point along the Sequential Intercept Model.

- *“Peer support...was the best thing that could have happened. To learn from someone who had successfully reentered society with MH issues really helped!”*

Critical Points along the SIM Informed by Lived Experience

3. **Consistent, statewide education and training are needed on the importance of jail diversion and how to access resources for families, stakeholders, schools, and law enforcement.**
 - *Respondents reported both positive and negative experiences with law enforcement with a direct correlation between the amount of training received by the officer. Respondents were very complimentary and grateful for encounters with CIT-trained officers.*

Critical Points along the SIM Informed by Lived Experience

4. **Mental health care is health care; coordination between mental health and primary care is the most effective.**
 - *“People do not understand that this is a disease just like heart disease.”*

Critical Points along the SIM Informed by Lived Experience

5. **Cultures of deescalation improve outcomes. Solitary confinement creates significant adverse effects for many.**
 - *“I was placed in solitary for disciplinary reasons where I could hear screaming and banging all day and night. It was quite traumatic.”*

Critical Points along the SIM Informed by Lived Experience

6. **There is a need for greater access to an array of crisis-related services including mobile teams, calm-down centers, and emergency detention.**
 - *Participants reported that when a crisis occurred, they were not aware of community resources providing mental illness or IDD services.*

Critical Points along the SIM Informed by Lived Experience

7. **Court participants are more successful with treatment when they feel they are respected, understood, and treated fairly. Courts can actively work to decrease stigma which discourages individuals from seeking treatment.**
 - *One family remarked that individuals were denied treatment because they were blamed, being told, “it's a behavior not a psychiatric problem.”*
 - *“I thought I was just bad!”*

Critical Points along the SIM Informed by Lived Experience

8. Information sharing is essential to plan effective services for people with mental health or IDD needs.
 - *HIPAA is “an enormous barrier.” Respondents encountered barriers in communicating information about their loved one’s history to professionals in every stage of the SIM.*
 - *One family member knew her son was in a hospital but could not provide information to his caregivers because the hospital would not take any information from her, despite her son being in such a severe psychosis that he was unable to communicate.*

Critical Points along the SIM Informed by Lived Experience

9. **Continuity of medication provides the best opportunity for recovery and successful re-entry.**
 - *“Access to medication is extremely uncertain in most county jails and continuity of medication between jails and prisons and hospitals is very poor.”*
 - *“While he was in...any jail, [he] only had access to medication because I found a way to get his prescription filled enough times and took the bottles to the jails.”*

Critical Points along the SIM Informed by Lived Experience

10. Stable housing improves outcomes by reducing jail days, providing diversion options, and improving re-entry success.

- *Participants identified housing as a serious issue.*
- *“The more one is in jail, the harder it is to get housing.”*