



CARE

(Community Assistance, Recovery and Empowerment)

Act

California Health & Human Services Agency
Person Centered. Equity Focused. Data Driven.

Data Collection, Reporting & Evaluation Ad Hoc Group Meeting

October 16, 2023

California Health & Human Services Agency

Person Centered. Equity Focused. Data Driven.



1. Welcome and Introductions

Virtual Meeting Guidelines

- Meeting is being recorded
- Zoom captioning enabled

Members

- Mute/Unmute works for members and policy partners.
- Stay ON MUTE when not speaking and use the “raise hand feature” if you have a question or comment.
- Please turn on your camera as you are comfortable

MEMBERS OF THE PUBLIC will be invited to participate during public comment period

Data Collection, Reporting & Evaluation Ad Hoc Group Members

Co-Chairs

- Keris Myrick
- Beau Hennemann

Special Advisor

- Katherine Warburton

Facilitators (Desert Vista Consulting)

- Karen Linkins
- Jennifer Brya
- Ruby Spies
- John Freeman

Members

- Alison Morantz
- Amanda Geipe
- Dawn Williams
- Dr. Sharon Ishikawa
- Jennifer Hallman
- Khatera Aslami-Tamplen
- Matt Tuttle
- Robert Beattey
- Ruth Hollman
- Sean Evans
- Susan Wilson
- Tami Mariscal

2. Goals of this Ad Hoc Group

CARE ACT Working Group

- Working group began in early 2023 as a mechanism to **receive feedback from partners to support successful implementation** and help key constituents understand policy and program progress who can then **disseminate accurate information**.
- Meets quarterly during the implementation of the CARE Act through December 31, 2026.
- Representation from families, cities and counties, behavioral health providers, judges, legal counsel, peer organizations, disability rights and racial equity stakeholders, and housing and homelessness providers.
- Provide feedback on implementation activities including:
 - Annual report and evaluation plan, including data collection and reporting
 - TA/training for counties, volunteer supporters, legal counsel, judges, etc.
 - County implementation progress
 - Housing access
 - Other emerging issues

Ad Hoc Group Overview

- Three initial advisory Ad Hoc groups have been formed to address:
 1. Services and Supports
 2. Training, Technical Assistance, and Communication
 - 3. Data Collection, Reporting, and Evaluation**
- Each will have cross cutting perspectives from:
 - Peers, Families, Lived Experience
 - Racial Equity and Social Justice
 - Providers

Ad Hoc Group Purpose and Goal

Data Collection, Reporting, and Evaluation

- Provide feedback on implementation activities including annual report and evaluation plan, including data collection and reporting
- Recommend additional types of outcomes to measure and track related to the effectiveness and impact of the CARE Act

Ad Hoc Group Operations

- Meetings of the Working Group and Ad Hoc groups shall be open to the public and subject to Bagley-Keene Open Meeting Act requirements.
- Ad hoc groups are anticipated to meet in October and potentially December of 2023
 - Additional meetings likely in January, March, April, June, July, September, October, and December of 2024
 - CARE Act Working Group meets November 8, 2023 and then in February, May, August, and November of 2024

Ad Hoc Group Approach

- Members will be respectful of each other's expertise and any differences of opinion.
- This is not an oversight or voting group. The goal is to generate ideas and solutions aimed at successful implementation of the CARE Act.
- Members are encouraged to be brief and brilliant. Keep the discussion moving to allow for new ideas from all group members.
- Members understand and acknowledge that CalHHS has a responsibility to implement the CARE Act as enacted in statute.
- Meeting agendas will be prepared and posted online in advance of a meeting. Members are encouraged to suggest agenda items.

3. Overview of Issues to Address and Q+A



Why should we CARE?

California Health & Human Services Agency
Person Centered. Equity Focused. Data Driven.

Schizophrenia Spectrum Disorder

- Usually diagnosed in late teens or early adulthood
- Often has a prodrome – symptoms of functional deterioration that precede psychotic symptoms
- Prevalence around 1%
- People with schizophrenia die 20+ years earlier than the rest of us
- One of the top 15 leading causes of disability worldwide
- Primarily focused on schizophrenia and schizoaffective disorder

Symptoms

Hallucinations- perceiving things that are not there, usually voices

Delusions- misperceiving reality through false beliefs, often paranoia

Disorganization – in speech and behavior

Negative symptoms - diminished emotional expression and avolition

Schizoaffective disorder includes a mood component

The majority of patients are not aware that they are ill

People with Schizophrenia often don't know it

- Poor insight is a **lack of awareness of having an illness**, of the deficits caused by the illness, the consequences of the disorder, and the need for treatment
- Poor insight is...
 - **Common in schizophrenia (~60%)**
 - Has a major impact on course of the illness and causes treatment nonadherence

What is happening now: case vignette

37-year-old transient male. Police called when patient refused to leave Jack in the Box. Police asked him to step outside and he complied. During a search, the police informed patient he was not welcome at the Jack in the Box. He became upset and tried to get out of the grasp of the officer. He then tried to call the police on an imaginary phone. He was talking to himself about the devil. He was missing his left eye and informed police he took out his eye because the devil told him to. The police attempted to handcuff patient and the patient struggled, was tasered multiple times. Charged with battery with injury on a police officer and resisting executive officer.

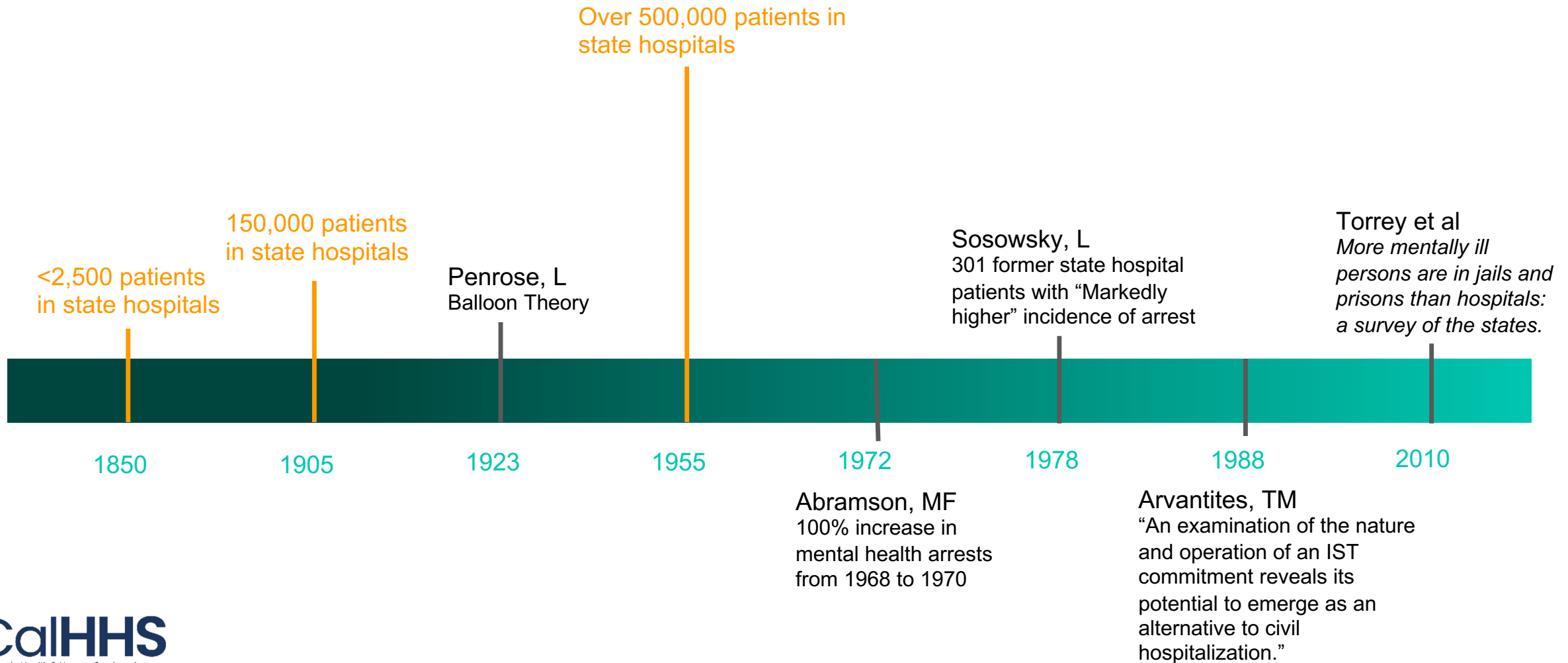
Outcomes

While people with Schizophrenia make up only 1% of overall population, they make up:

- 20-30% of homeless population
- 15% of state prison population
- 24 % of jail population

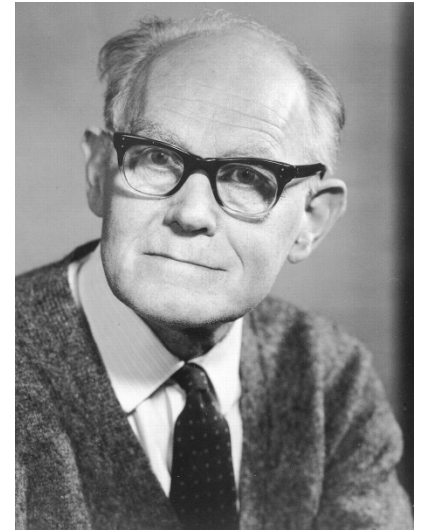
HUD 2015 AHAR to Congress, Ayano et al. BMC Psychiatry (2019), Garcia and Haskins (2020), US DOJ (2006)

State Hospital overutilization: An historic problem

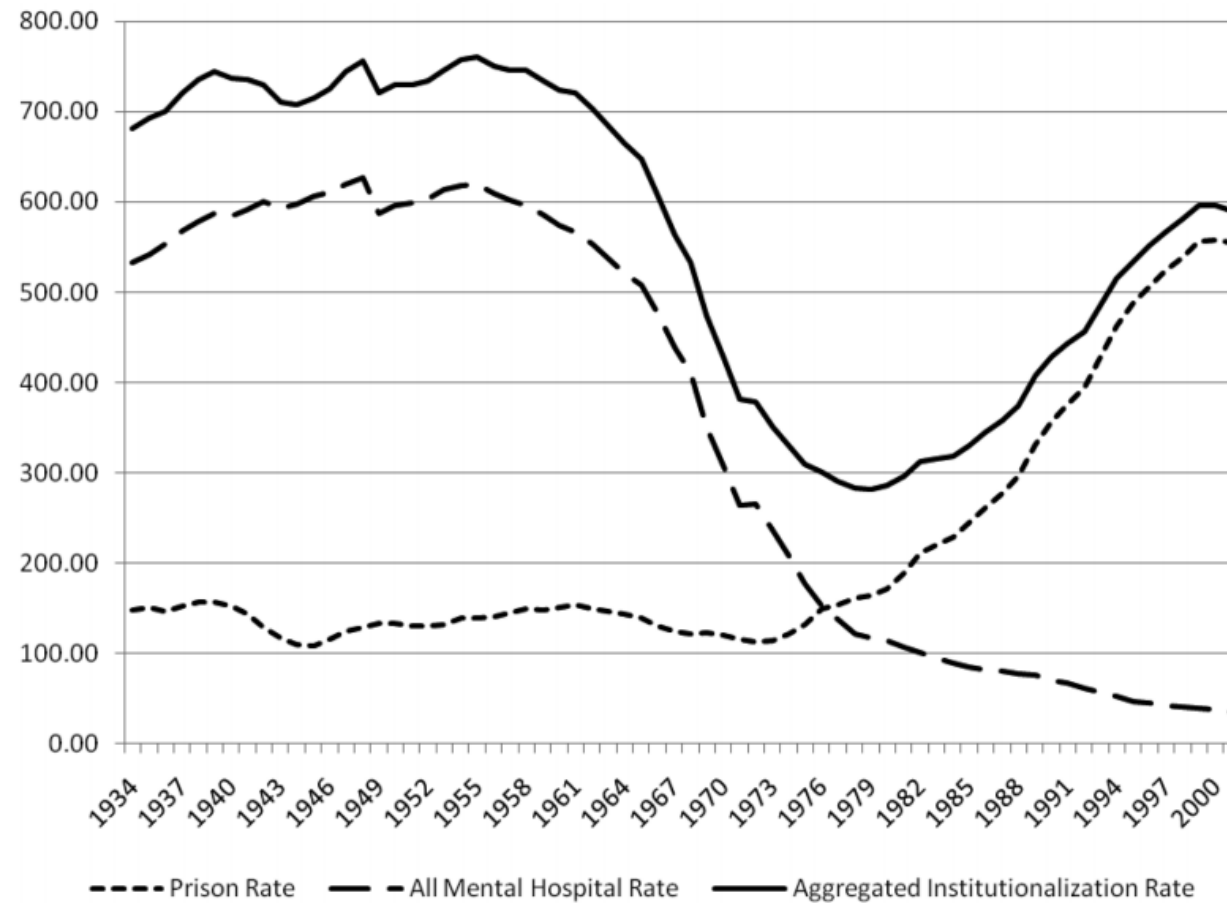


Penrose Effect/Penrose's Law

In 1939, British psychiatrist Lionel Penrose described an inverse relationship between the number of patients in mental hospitals and the number of sentenced adult prisoners



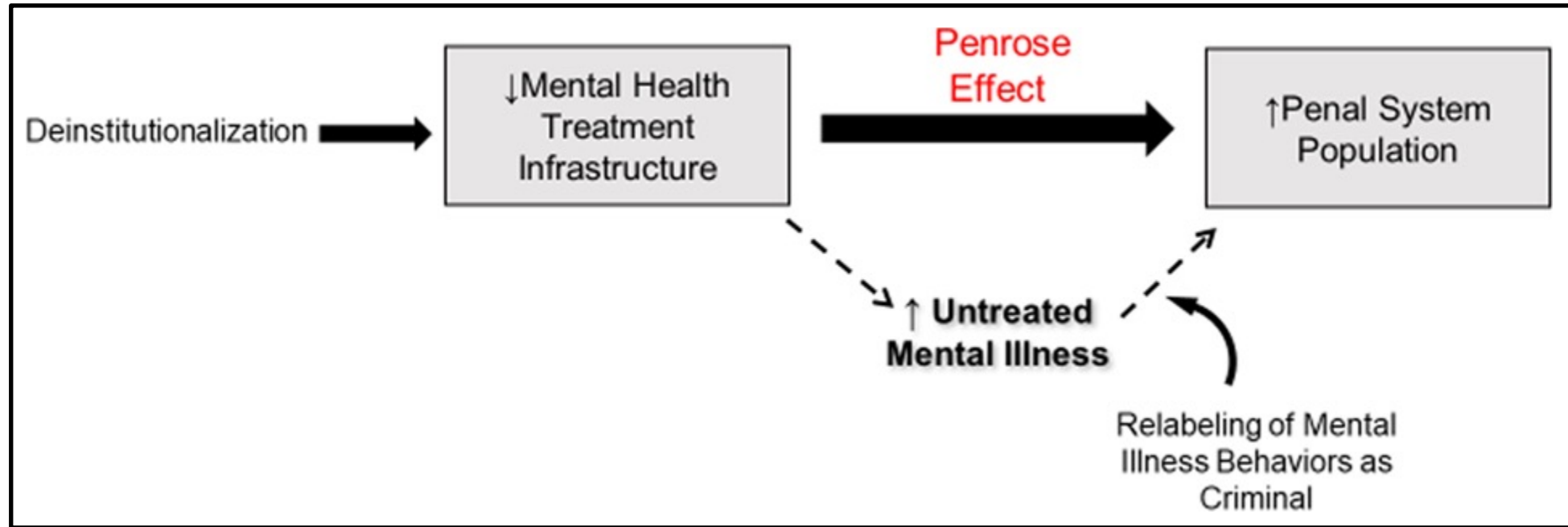
US Rates of Institutionalization per 100,000



Psychiatric Bed Capacity

- Reductions to local psychiatric bed capacity were significantly correlated with an average increase of 256.2 jail inmates

Penrose Explained



Forensic Patients in State Hospitals



- 74%↑ in the number of forensic patients in state hospitals from 1999 to 2014
- 72%↑ the number of IST patients from 1999 to 2014

UC Davis Napa Research

- Started in 2008
- Large sample
- Initially Napa specific
- Expanded into statewide protocol

The Incompetent to Stand Trial Crisis

- RESULTS
 - 67% of these patients are experiencing homelessness when they enter the system,
 - 47% have not received Medicaid reimbursable mental health services in the six months prior to entry, and
 - 70% are rearrested within 3 years of discharge.
 - Referrals are skyrocketing
- This cycle contributes to long-standing inequities where those with severe behavioral health conditions experience greater rates of chronic homelessness and incarceration.

Rankings

- Responses ranked high in importance*:
 - Inadequate general mental health services (3.45)
 - Inadequate crisis services in community (3.71)
 - Inadequate number of inpatient psychiatric beds in community (3.78)
 - Inadequate ACT services in community (4.22)

*Lower numbers means a higher (more important) ranking

Link Between Beds and Arrest

Study of police discretion indicates that when confronted with the choice between arresting a person with mental illness or bringing that person to an emergency room, **the most important factor was whether the officer thought that person would be admitted to a hospital bed.**

- Green, TM International Journal of Law and Psychiatry, 1997

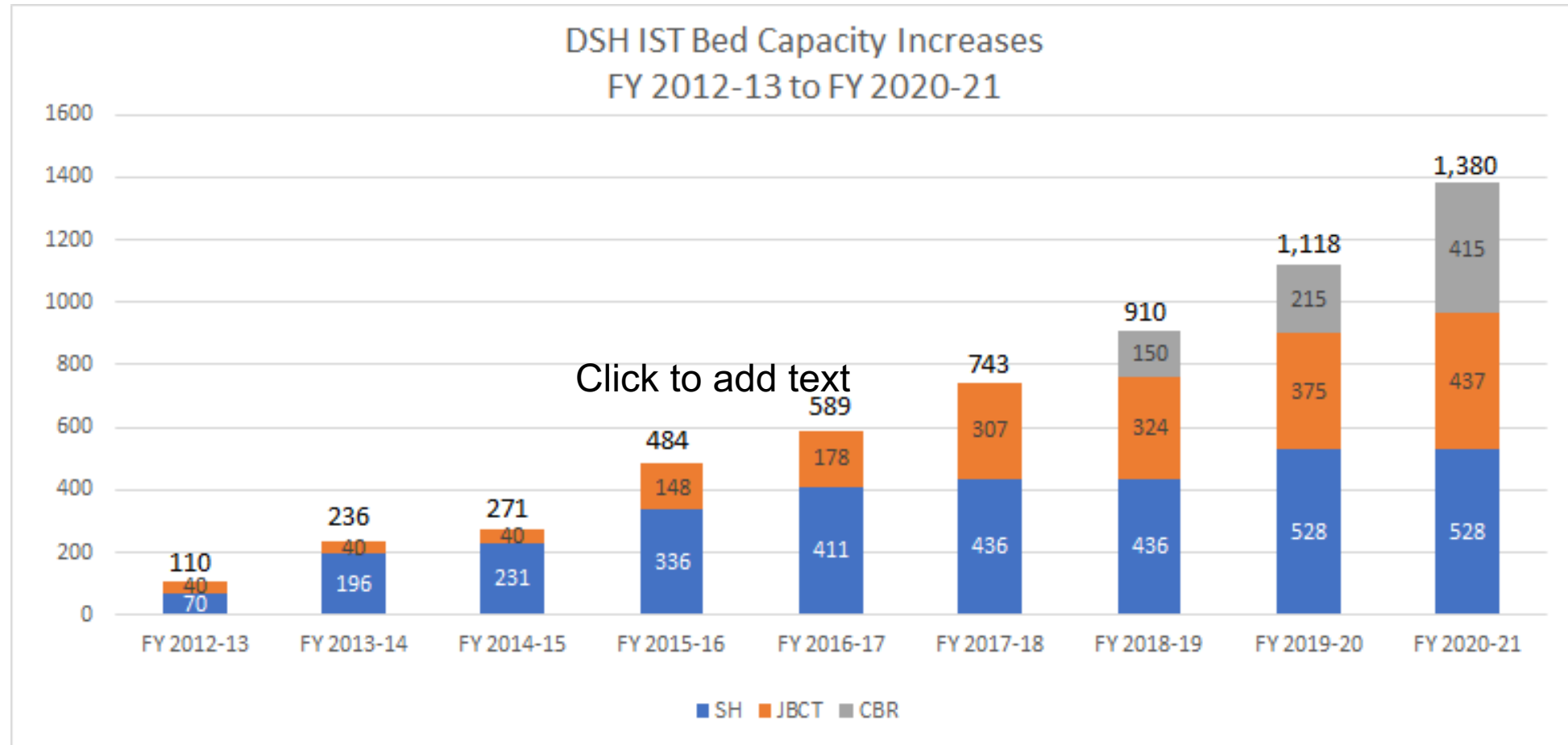
Factors positively associated with high-frequency incarceration included:

- Schizophrenia spectrum/bipolar affective disorder
- Homelessness

What is happening now: case vignette 2

- 45-year-old transient male entered a sandwich shop. Believed he owned the establishment. Locked the back door and put crates in front of it, per his comments to secure it because it “was busted”, and asked for a sharpie and paper to put an out of order sign on the back door. Proceeded to bathroom, cleaned it, and expressed concern about someone slipping due to excess water on the floor. Asked the clerk for the money in the register stating, “Don’t worry I’m the owner.” Was denied without incident. Then asked for a sandwich. Clerk ran out and into the storefront adjacent for help. At the time of arrest was delusion about owning stores and talking about “Tony the Tiger”. Pt charged with **false imprisonment and attempted robbery.**

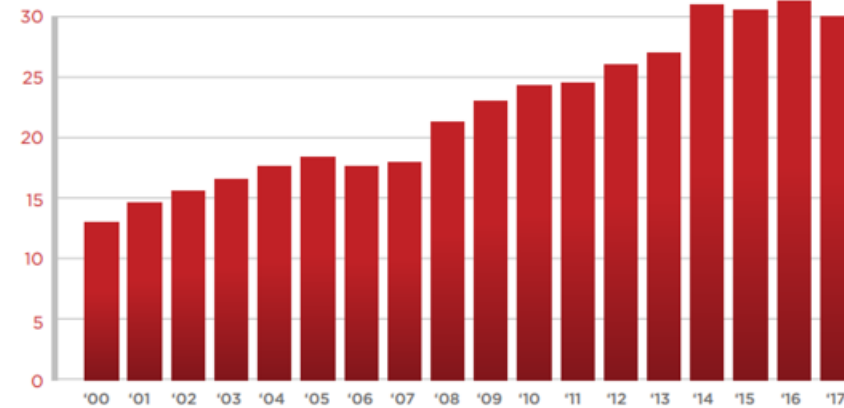
DSH Capacity Increases



California Outcomes

State Prison Population Receiving Mental Health Treatment

Percent of State Prison Population Receiving Mental Health Treatment, 2000-2016¹

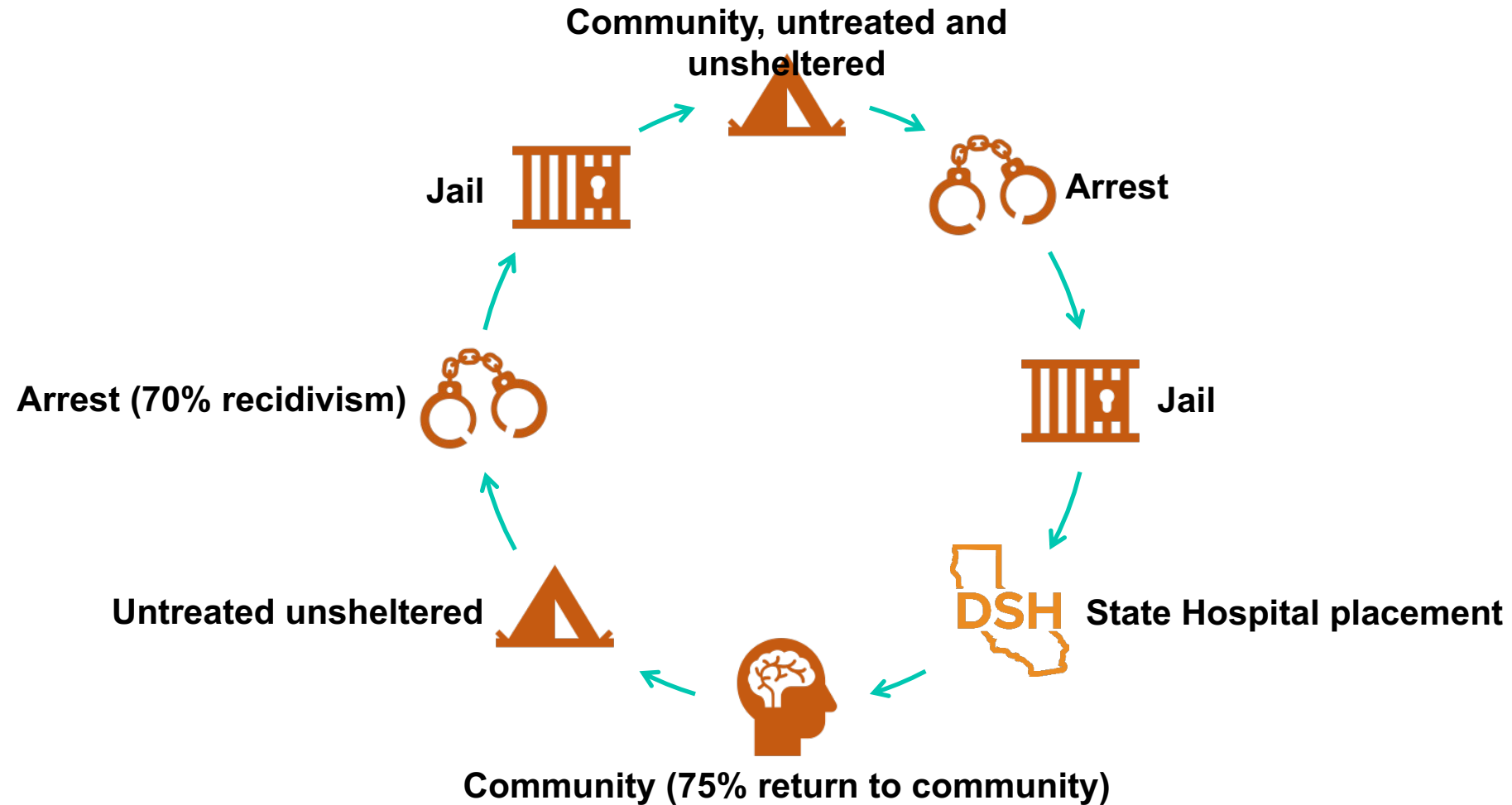


Stanford Justice Advocacy Project 2017.

Why?: Our Hypothesis

- Individuals with Schizophrenia Spectrum Disorders are drifting into an untreated, unsheltered condition.
- These conditions are leading to increased contact with police and criminal charges.
- This increased contact is leading to a surge in IST referrals to state hospitals.
- Building more state hospital beds will only exacerbate the problem long term.
- IST restoration is not adequate long term treatment plan.
- So, what can we do?

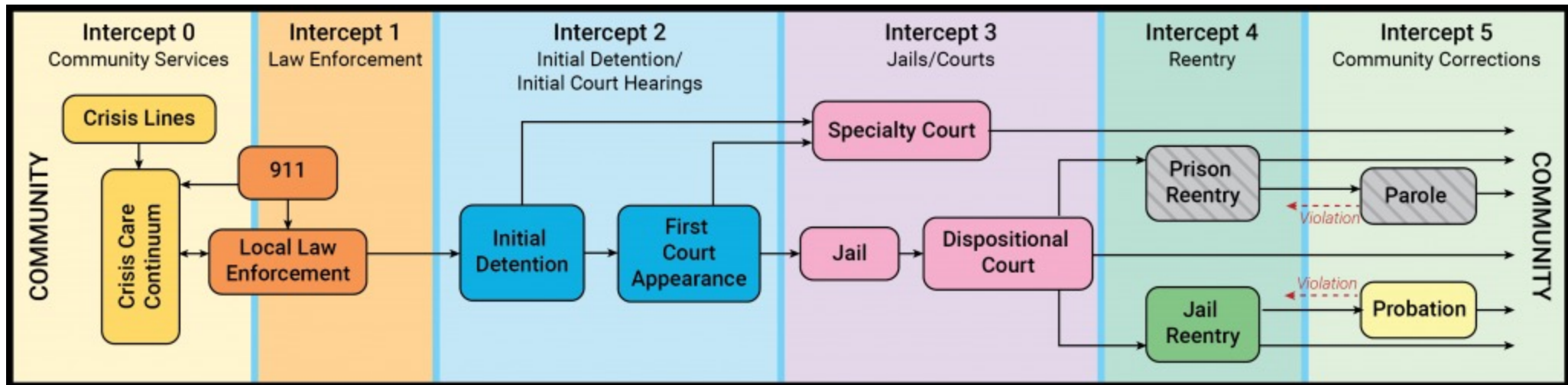
Criminalization Cycle



CARE is designed to break the cycle

- As a civil court process, CARE is an upstream diversion designed to break the cycle of homelessness, criminalization, and institutionalization
- The success of CARE will be based on whether this process can connect the respondent to the right services and supports including stabilization medications, wrap around behavioral health services, and housing.

Sequential Intercept Model (SIM)



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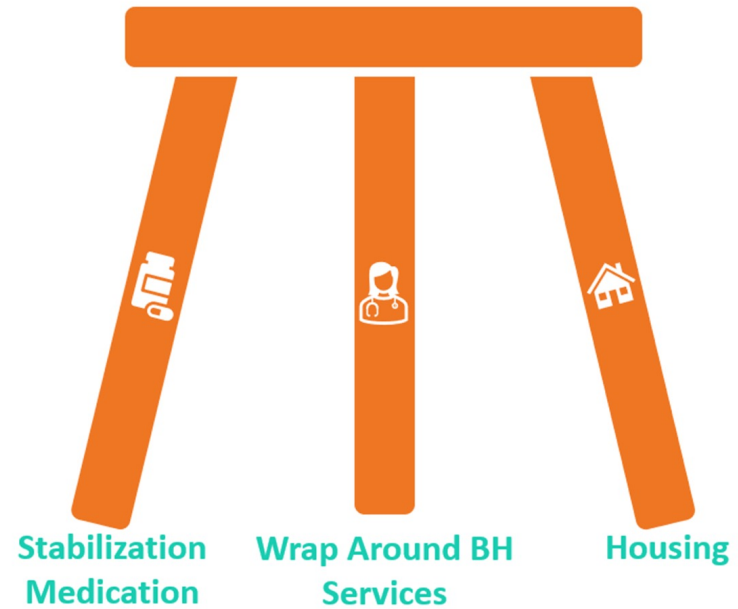
CARE Plan

- (b) “CARE plan” means an individualized, appropriate range of community-based services and supports, as set forth in this part, which include clinically appropriate behavioral health care and stabilization medications, housing, and other supportive services, as appropriate, pursuant to Section 5982.
- Should be based in the standard of care

Standard of Care- APA Guidelines

- 4. APA *recommends*(**1A**) that patients with schizophrenia be **treated with an antipsychotic medication** and monitored for effectiveness and side effects.*
- 10. APA *suggests*(**2B**) that patients receive treatment with a **long-acting injectable antipsychotic medication** if they prefer such treatment or if they have a history of poor or uncertain adherence.*
- 19. APA *recommends*(**1B**) that patients with schizophrenia receive **assertive community treatment** if there is a history of poor engagement with services leading to frequent relapse or social disruption (e.g., homelessness; legal difficulties, including imprisonment).*

Three-Legged Stool



Medication

- According to systematic reviews of observational and naturalistic studies, following treatment, **complete recovery or remission** occurs in:
 - ~38% of patients with multi-episode psychosis
 - ~55–57% of patients with first-episode psychosis
- Adherence to antipsychotics is associated with symptomatic and psychosocial remission, as well as community integration
- Effect on symptoms reduction overall compares with treatment for other chronic conditions such as high cholesterol and hypertension

Medication (continued)

- Possession of psychotropic medication reduces the odds of arrest.
- The combined effects of medication possession and outpatient services reduces risk of arrest even further.
- Effect size of antipsychotic medication is comparable to those for other chronic conditions such as hypertension, high cholesterol

AMA Principles of Medical Ethics

- The process of informed consent occurs when communication between a patient and physician results in the patient's authorization or agreement to undergo a specific medical intervention.
- Requires an assessment of the patient's ability to understand relevant medical information and the implications of treatment alternatives and to make an independent, voluntary decision

Insight is necessary for medical-decision making capacity

Medication in CARE Act

5977.1(d)(3) A court may order medication if it finds, upon review of the court-ordered evaluation and hearing from the parties, that, by clear and convincing evidence, the respondent lacks the capacity to give informed consent to the administration of medically necessary stabilization medication.

Medication in Context

Forced
Medication

Clinical opportunity enabled by
Court Order

Voluntary
Informed
Consent

Services

Gold Standard is Assertive Community Treatment

- Evidence-based model backed by 50 years of research
- Designed to improve housing stability, medication adherence, and overall functioning
- 24/7 Access to multi-disciplinary care team in the community
- Intensive, coordinated, integrated, highly individualized care to meet the patient's needs, delivered by a team the patient trusts
- Medication management and rehabilitative and supportive services
- Many studies support use of ACT, with outcomes such as:
 - reduction in jail/prison booking
 - reduction in days incarcerated
 - reduction in psychiatric hospitalization
 - Improved medication adherence, housing stability and overall functioning

Housing

- Maintaining stability and staying connected to treatment is extremely difficult when unhoused
- Clients/Respondents participating in the CARE Process will need a diverse range of housing options, including:
 - Clinically enhanced interim or bridge housing
 - Licensed adult and senior care facilities
 - Supportive housing
 - Housing with family and friends

What is happening now: case vignette 3

35-year-old male transient male. Police called, arrived as patient was on roof, pulling the roofing tiles off the residence and throwing roofing tiles off the roof. He took off his clothing. Officers stated patient then threw roofing tiles at them. One tile landed a foot from officers. Broke skylight, doused himself with water from spout. No response to taser. Ran away and was apprehended. Agitated and talking to himself. Charged with **felony aggravated assault** on a police officer (**AWDW roof tile**), and **felony vandalism**.

Recap

- Early intervention is key, and too often absent
- People are very, very sick
- People are too often involved with the criminal justice system, homelessness, and not being served
- The three-legged stool of medications, 24 hour coordinated services, and housing forms the foundation for recovery



Thank you!

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Discussion and Q&A

- What are the key considerations and opportunities for this group?

4. Discussion of Short-Term Strategies

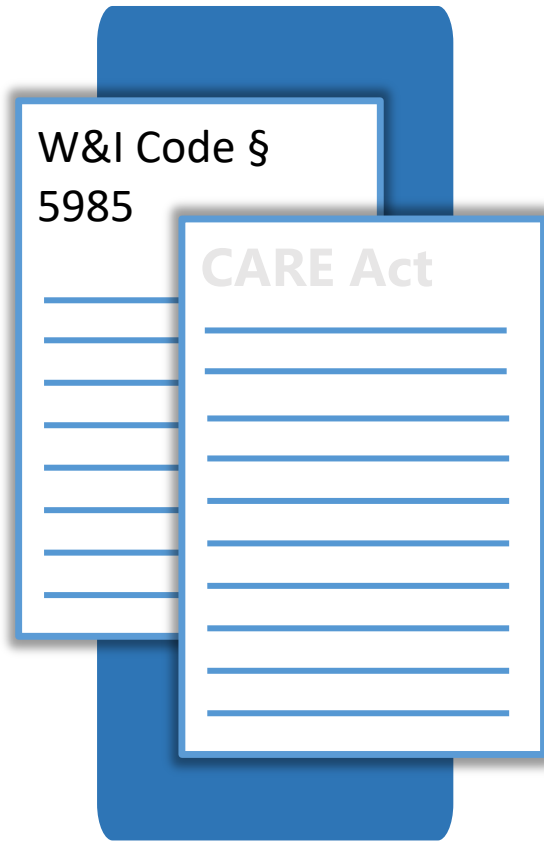
Adhoc Workgroup Meeting: Update on CARE Act Data Collection & Reporting

October 16, 2023

Serene Olin, HMA, on behalf of Medi-Cal Behavioral Health Policy Division

Andy Potter, Quality & Population Health Management, California DHCS

BH Information Notice 23-052



Purpose: Provide Guidance to Counties on Data Reporting Requirements

- » DHCS is required to develop and publish an annual report. The report must include, at a minimum, the data and information listed in subdivisions (e) and (f) of W&I Code section 5985.
- » **DHCS's Responsibility:** Provide technical assistance and consultation to support CARE Act implementation, including
 - Development of a Data Dictionary to support consistent data collection
 - Formation of a data collection tool to facilitate reporting by Judicial Council and Counties
 - Delivery of ongoing technical assistance and consultation to County Behavioral Health Agencies
 - Organization of quality assurance processes for data integrity
- » **County Behavioral Health Agencies Responsibility:** Provide data specified by DHCS related to CARE Act participants, services, and supports for use in the annual reports.

Source: W&I Code, § 5985

CARE Act Resource Center

- **CARE Data Reporting Requirements**

Released October 3rd, 2023: [BH Information Notice No.: 23-052](#)

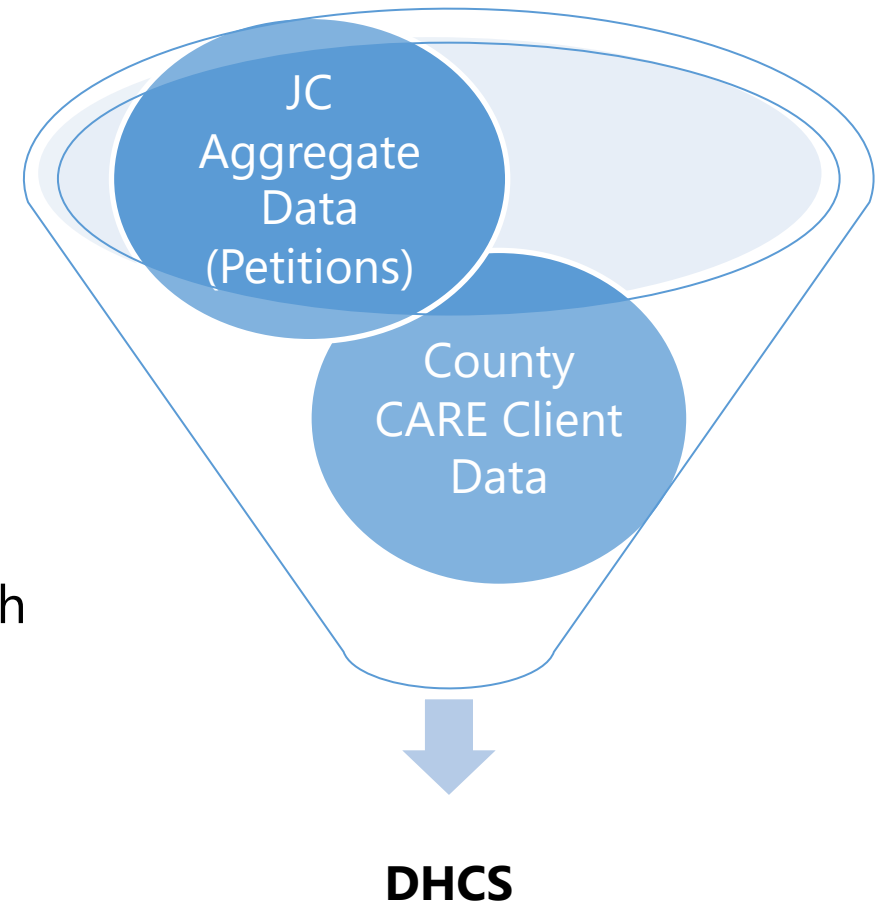
- Enclosure: [Data Dictionary Version 1-0](#)

Resources:

- Asynchronous Training video and slides:
<https://care-act.org/training-material/part-1-care-act-data-dictionary-overview/>
- Supplemental Material:
 - Data FAQ document
 - Data Workflow Document
 - Summary Table of Data Elements

CARE Participants and County Clients

- » **Judicial Council** will capture **aggregated** trial court data on all petitioned respondents.
- » **County Behavioral Health Agencies** will capture respondent data at the **individual level** on:
 - Petitions they initiate with CARE Court
 - Petitions for which the court orders them to investigate and file a written report
- » For petitions that result in an individual receiving county BH services/supports, County Behavioral Health Agencies are required to track **three CARE pathways over time**:
 1. Clients with a CARE plan
 2. Clients with a CARE agreement
 3. *Elective Clients



*Elective clients are defined as former CARE respondents who meet prima facie and CARE criteria but are diverted to county services and supports through voluntary engagement, resulting in the petition being dismissed by the court.

Data Submission: Reporting Schedule

- » Data from October 1 – December 31 due by March 1, 2024
- » Collect data on a monthly basis and submit it within 60 days following the close of the reporting period
 - Alternative: Counties can opt to submit data monthly
- » Counties must adhere to the reporting and submission schedule regardless of implementation date.

Reporting Period	Submission Deadline
January 1 – March 31	May 30
April 1 – June 30	August 29
July 1 – September 30	November 29
October 1 – December 31	March 1

CARE Act Annual Report & Independent Evaluation

CARE Act Annual Report

Annual Report

Collect data to monitor the performance of CARE Act model implementation.



Include outcome measures to assess the scope and impact of the CARE Act model.



Conduct a health equity assessment of the CARE Act to identify demographic disparities to inform disparity reduction efforts.



Produce the annual report
July 2025, 2026,
2027, & 2028

Independent Evaluation

Conduct survey of program participants



Conduct an independent evaluation to highlight racial, ethnic, and other demographic disparities



Include analyses regarding the impact of the CARE Act on disparity reduction efforts.



Develop legislative reports in year 3 and year 5 of implementation.

Annual Report & Independent Evaluation

Annual Report

Identify key questions of interest, and stories we can tell from the data to inform CARE implementation

Independent Evaluation

- Independent Evaluation Scope of Work

Questions



5. Public Comment

Public Comment

Public Comment will be taken on any item on the agenda

There are 2 ways to make comments:

1. Raise hand on zoom to speak. If joining by call-in, press *9 on the phone.
2. We encourage email comment to CAREAct@chhs.ca.gov

****Please limit comments to 2 minutes****

NOTE: members of the public who use translating technology will be given **additional time** .

6. Meeting Wrap Up and Next Steps

Next Steps

- CARE Act Working Group meets November 8, from 11 am to 3 pm
- Training, Technical Assistance, and Communication ad hoc group meets next in December
- Data Collection, Reporting, and Evaluation Ad Hoc Group meets next in December
- Services and Supports Ad Hoc Group meets October 31st from 12:30-2:00pm

7. Adjourn and Thank you!