



CARE

(Community
Assistance,
Recovery and
Empowerment)
Act

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

CARE Act Working Group Meeting

August 9, 2023

California Health & Human Services Agency

Person Centered. Equity Focused. Data Driven.



Welcome and Introductions

*Stephanie Welch, MSW, Deputy Secretary of
Behavioral Health, CalHHS*

Working Group Members

Al Rowlett

Anthony Ruffin

Beau Hennemann

Bill Stewart

Charlene Depner

Chevon Kothari

Dhakshike Wickrema

Eric Harris

Dr. Fadi Nicolas

Harold Turner

Herb Hatanaka

Hon. Maria Hernandez

Jenny Bayardo

Jodi Nerell

Keris Myrick

Khatera Aslami

Kiran Savage

Lorin Kline

Matt Tuttle

Sarah Jarman

Stephanie Welch

Susan Holt

Tomequia Moss

Tracie Riggs

Tyler Sadwith

Dr. Veronica Kelley

Vitka Eisen

Xóchitl Rodriguez Murillo

Zach Friend

Zachary Olmstead

Virtual Meeting Guidelines

- Meeting is being recorded
- American Sign Language interpretation in pinned video
- Live captioning link provided in chat

Working Group 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

Working Group Overview – Operations

- The Working Group will meet quarterly during the implementation of the CARE Act through December 31, 2026.
- Working Group meetings will be a mix of in person and virtual, with in person meetings held primarily in Sacramento, but at times possibly in other locations throughout California.
- Working group members are expected to attend 75% of meetings each year, with the option of sending a delegate for the remainder.
- All meetings of the Working Group shall be open to the public and subject to Bagley-Keene Open Meeting Act requirements.

Working Group Overview Operations (continued)

OPERATIONS CONT.

- 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. Working Group members are encouraged to suggest agenda items.

CARE Working Group 2023 Meeting Date

- November 8, 2023

CARE Act Implementation Update

*Stephanie Welch, MSW, Deputy Secretary of Behavioral Health,
CalHHS*

Tyler Sadwith, Deputy Director, Behavioral Health, DHCS

*Charlene Depner, Director, Center for Families, Children & the
Courts | Judicial Council of California*

CalHHS Roles and Responsibilities (overall)

Overall

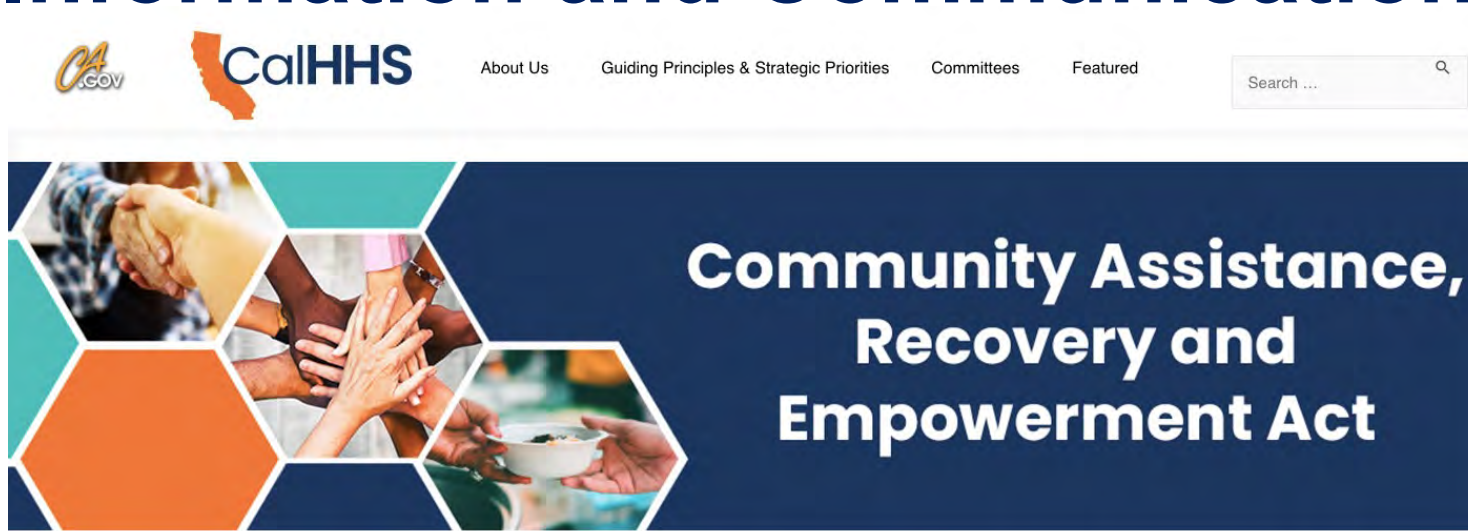
- Lead coordination efforts with and between the Judicial Council and DHCS
- Engage with cross sector partners at city and county level, individually and through collaboratives and convenings (3rd Cohort 1 Convening this week)
- Coordinate with partners and a diverse set of stakeholders via regular meetings – including county associations (*CSAC and key affiliates like CBHDA, RCRC, CA Association of PA/PC/PG, CWDA, etc.*)
- Support DHCS training, technical assistance and evaluation efforts, as well as implementation of Behavioral Health Bridge Housing program, monitor housing related needs throughout implementation
- Support communications through a website dedicated to the CARE Act, including a listserv, respond to media, legislature, and other stakeholder inquiries, provide proactive media and community engagement and outreach

CalHHS Roles and Responsibilities (Working 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**.
- 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

Information and Communication Tools



Visit the [CalHHS CARE Act website](#) for updated information and communication tools, including:

- Quarter 2 Update: [English](#) / [Spanish](#)
- CARE Informational Webinar (updated 12/19/22): [Video](#) / [Slides](#)
- [SB 1338](#)
- [Department of Health Care Services \(DHCS\) CARE Act Website](#)
- [Judicial Council of California \(JCC\) CARE Act Website](#)

DHCS CARE Act Implementation Update

Tyler Sadwith, Deputy Director, Behavioral Health, DHCS

CARE Act Working Group Judicial Council Progress Report

August 9, 2023



CARE ACT PROGRESS UPDATE: JUDICIAL COUNCIL

- **Budget:** Provided FY2023-24 funding to the Judicial Branch for CARE Act implementation, including funding for early implementation in Los Angeles. Increased funding for representation by Qualified Legal Services Providers and Public Defenders.
- **Funding for Courts:** Allocation Methodology for Cohort 1 Courts approved by Judicial Council and will go out in August distribution. Allocation for Los Angeles going through the approval process awaiting review by Judicial Branch Budget Committee, moves to Judicial Council for final approval in September.
- **Court Rules and Forms:** Rules and Forms approved at the May 12 Judicial Council meeting, effective September 1, 2023 and now available to courts on the Judicial Resources Network. Forms have been enhanced for ease of use; Document Assembly Program is in testing phase.

Judicial Council Update (continued)

- **Training and Technical Assistance:** Cohort 1 and Los Angeles Training began in June. All trainings have been recorded for access on the Judicial Resources Network. Groups trained: Cohort 1/LA Courts, Judges, Clerks, Self-Help Center staff; all court staff. Checklists to support court procedures; Flow Chart of the court process; resources for judges.
- **Information Resources:** Adult Mental Health site on [Judicial Council website](#); background information, fact sheets and infographics for Self-Help Centers and for the public on the [public website](#). Forms will be added to the [Judicial Council's Self Help Guide](#).
- **New Care Court Tool Kit** – Start-up resources for all courts-in development.

Judicial Council Update (continued)

- **Data Collection and Reporting:** CFCC, Office of Court Research, and Information Services have revised the data dictionary to conform with AB 102 and will meet with court data specialists on Aug 14 to prepare for implementation. State Bar is developing data reporting for legal services. Initial meeting with DCHS regarding data submission to them.
- **Self-Help Center Readiness:** Readiness Site Visits, Check lists, Training, Information Resources
- **Representation:** San Francisco Court will be represented by Legal Services Providers. All other cohort 1/LA courts will be represented by Public Defenders.
- **Communications: Cohort 1/LA:** Care Act Communication Hub and JC CARE Act mailbox. Monthly meetings with courts and bimonthly convenings with courts and local partners. **All Courts:** Online Judicial Resources Network, Listserv.

Updates on Cohort 1 County Implementation

Tracie Riggs, County Administrator, Tuolumne County

Dr. Veronica Kelley, Chief, Mental Health and Recovery Services, Orange County



CARE Court

Dr. Veronica Kelley



What is CARE Court?

Community
Assistance
Recovery &
Empowerment

Care Court is a “new civil court process” established to:

- Focus counties and other local governments on serving persons with **untreated schizophrenia spectrum or other psychotic disorders**.
- Provide **behavioral health and other essential resources** and services.
- **Protect self-determination and civil liberties** by providing legal counsel and promoting supported decision making.
- **Intervene sooner** in the lives of those in need to provide support.

Who does this program serve?

- Adults, 18 years or older.
- Diagnosed with a Schizophrenia Spectrum and Other Psychotic Disorders.
- Currently experiencing behaviors & symptoms associated with severe mental illness (SMI).
- Not clinically stabilized in on-going voluntary treatment.
- At least one of the following:
 - Unlikely to survive safely without supervision and condition is substantially deteriorating.
 - Needs Services & supports to prevent relapse or deterioration, leading to grave disability or harm to others.
- Participation in CARE Plan or Agreement is the least restrictive alternative.
- Likely to benefit from participating in a CARE Plan or Agreement.



Who can petition?

Family/Home

- Persons with whom respondent resides.
- Spouse, parent, sibling, adult child, grandparents, or another individual in place of a parent.
- Respondent (i.e. self petition)

Community

- First responder (e.g., firefighter, paramedic, mobile crisis response, homeless outreach worker)
- Director of a Hospital, or designee, in which the respondent is hospitalized.
- Licensed behavioral health professional, or designee treating respondent for mental illness.
- Director of a public /charitable organization providing behavioral health services or whose institution respondent resides.

County

- County behavioral health director, or designee
- Public Guardian or designee.
- Director of adult protective services or designee.

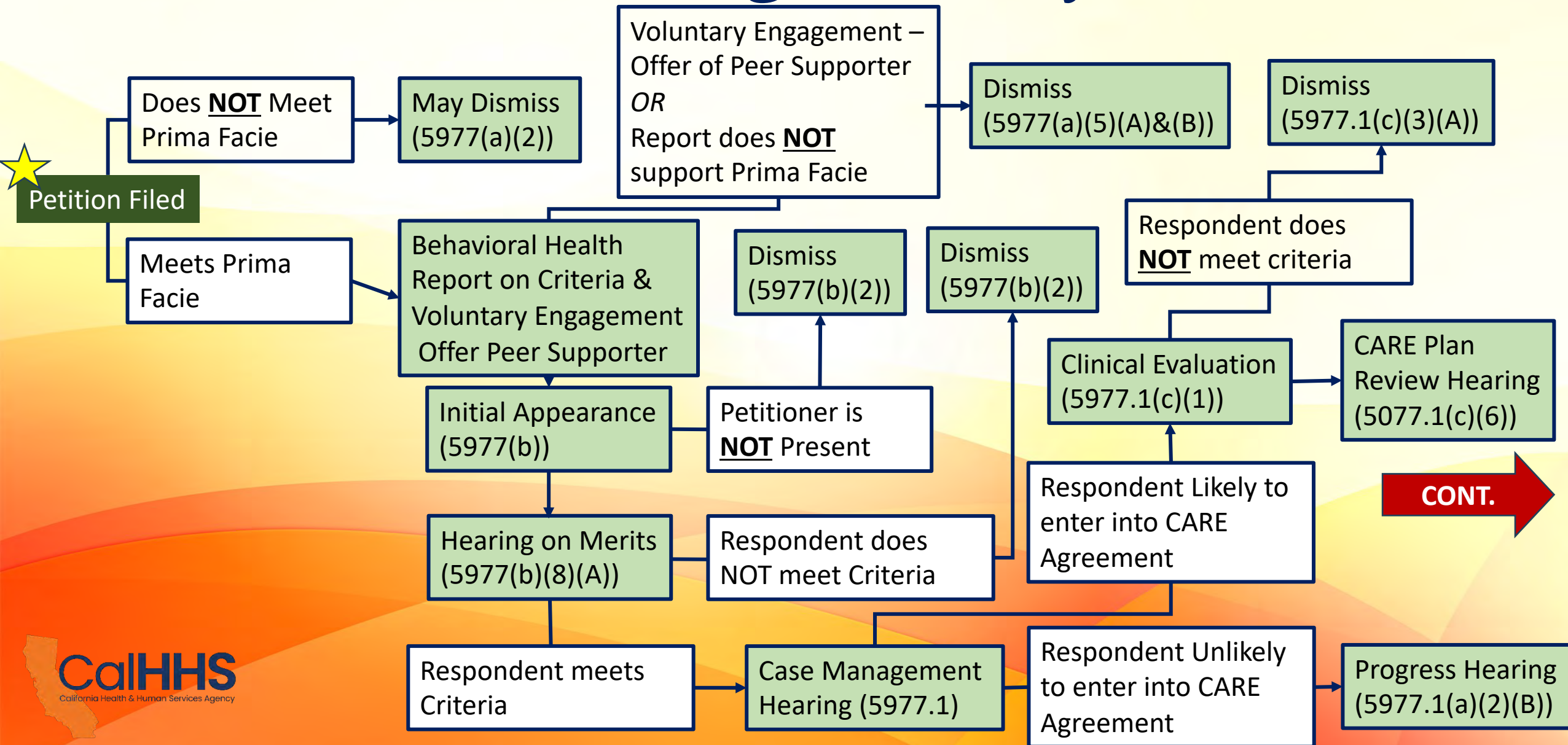
Tribal Jurisdiction

- Director of a California Indian health services program, California tribal behavioral health department, or designee.
- Judge of a tribal court located in CA, or designee.

How to file a petition?

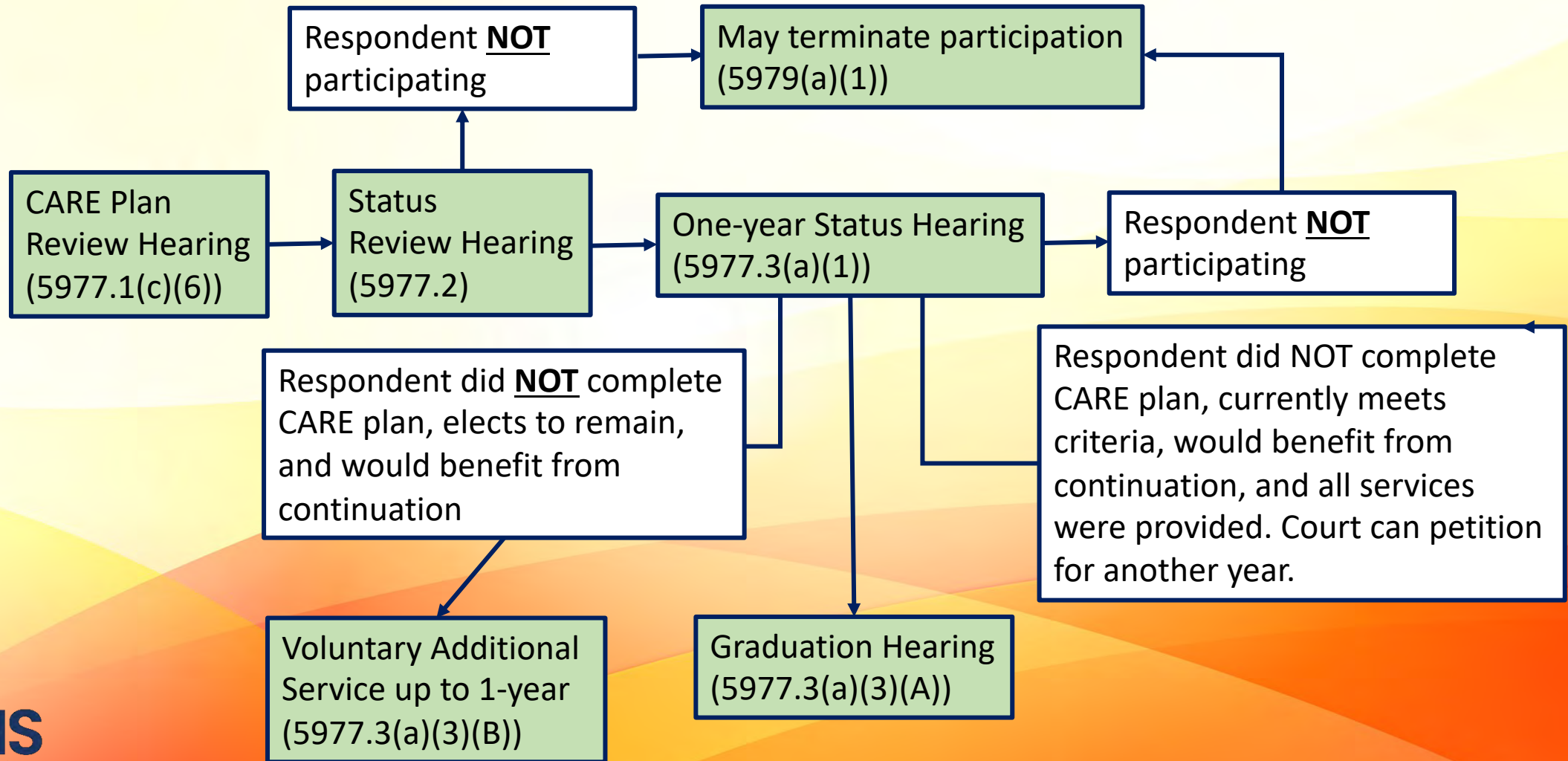
- Complete petition (CARE-100) – remember to fill out ALL requested information.
- Additionally, provide the required documentation.
 - Completed **Mental Health Declaration (CARE-101)** from licensed behavioral health provider OR;
 - Evidence the respondent was detained for a minimum of TWO periods of intensive treatment (**WIC 5250 holds**), the most recent episode being within the last 60 days.

CARE Court in Orange County



CARE Court in Orange County *Continued...*

CONT.



What is in a **CARE Agreement/Plan?**



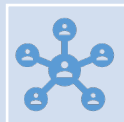
Behavioral Health Service



Medication Management



Housing Resources



Social Services & Supports

How is **CARE Court** **Different** From AOT?

CARE Court has a narrow list of mental illness diagnosis which qualifies.

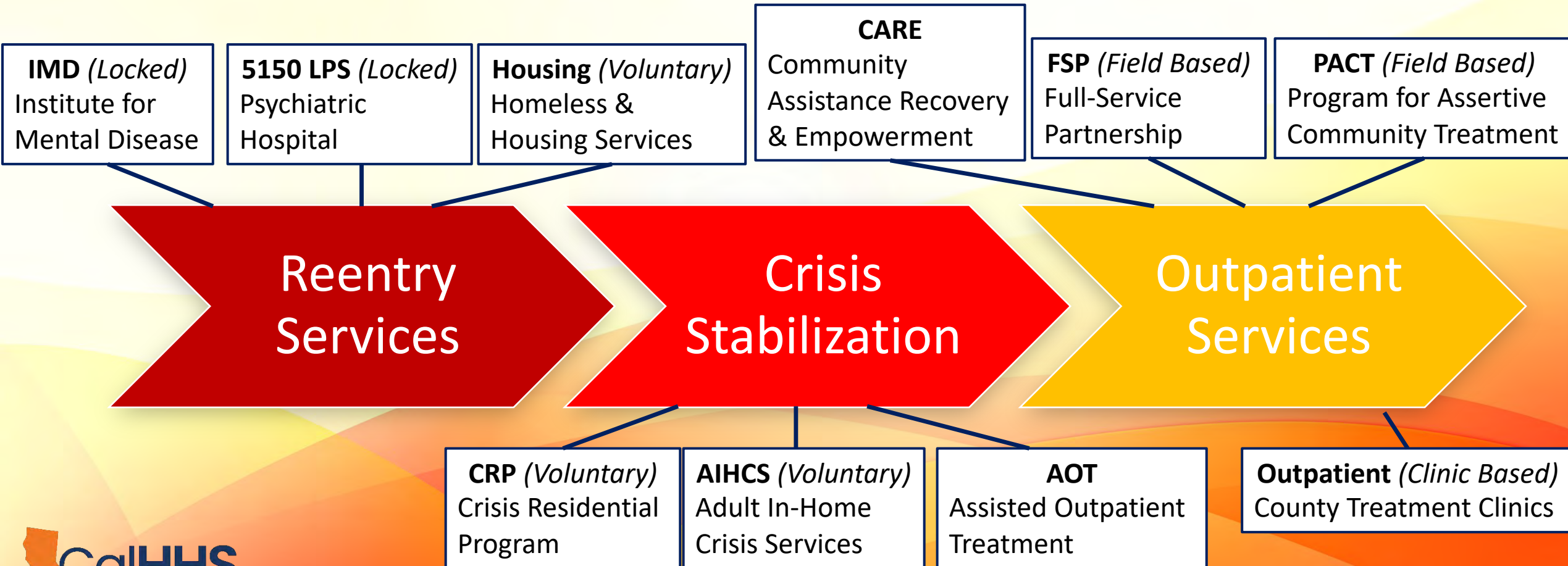
CARE Court has large list of qualifying petitioners.

CARE Court allows for a supporter to assist with treatment team and supportive decision making.

CARE Court duration is for one year (with a second year granted if necessary).

CARE Court will be available in every county statewide by 2025 – no matter the insurance plan.

Other **Orange County Programs** Available





 *Navigator.org*



Tuolumne County



Planning Team: County of Tuolumne

- Tracie Riggs, County Administrative
- Sarah Carrillo, County Counsel
- Maria Sullivan, County Counsel
- Rebecca Espino, Health and Human Services Director
- Tami Mariscal, Behavioral Health Director
- Scott Gross, Public Defender
- Michelle Clark, Department of Social Services Director
- Michael Roberson, Homelessness Coordinator
- Dana Gross, Public Defender Attorney

Planning Team: Court

- Honorable Hallie Gorman Campbell
- Hector Gonzalez, CEO Superior Court
- Stacey Robbins-Podvin, Court Program Manager
- Cassandra Vigardt, Court Program Manager for Care Court

Notable Accomplishments-Tuolumne County

- Recurring planning meetings with Court staff
- June 20, 2023: BH personnel requests approved by BOS
 - Clinical Psychologist
 - Forensic Program Specialist
 - BH Peer Specialist (certified)
 - Legal Assistant
- July 7, 2023: closed escrow for 25-room navigation center
- Community engagement and education schedule complete
 - ☐ July 12th Behavioral Health Advisory Board
 - ☐ July 18th Board of Supervisors
 - ☐ August 23rd In-person presentation for petitioners and CBO's
 - ☐ Facebook Live Sept. 6th event for general population (recorded)

Notable Accomplishments-Tuolumne County

- Court restructured and added staff for direct service in CARE Court and Self-Help Center.
- In process of procuring additional housing in the community to provide housing for CARE Court participants
- Behavioral Health has formed an internal planning team to create structure to the service delivery model for CARE Court participants.
- County Board of Supervisors approved all requested positions to support CARE Court

Cohort 1 Counties

1. LA
2. San Diego
3. Riverside
4. City County of San Francisco
5. Orange
6. Stanislaus
7. Glenn
8. Tuolumne

Cohort 1-Notable Challenges

- System to collect data for annual report from multiple jurisdictions
- Confidentiality
- Lack of standardized forms and templates
- Lack of developer resources to complete ECourt changes (CMS)
- Sustainable funding for County Counsel, Public Defender, and Public Guardian
- Conflicted community support to help mentally ill homeless
- Communities lack of understanding on homeless issues
- Details regarding reporting required of Public Defenders
 - Building the necessary staffing and IT to meet that requirement
- Information sharing between BH and Courts
 - Specifically, the ability for BH staff to gather information from other providers, unless there is a release.

Cohort 1 County Concerns

- Overlapping legislative changes (SB 43, MHSA modernization, IST, etc.)
- Staffing: the ability to hire the positions needed to successfully implement while already facing a significant workforce shortage in this area
- Setting the expectation with the municipal and community about what CARE Act is and is not. The impression many have is that this will “solve homelessness”
- Service of Process: Public Defend concerned about delivery by BH as they are the provider.
 - Public Safety interface with those in need
- Funding for non-medical/clinical services.
 - BH staff time spent in court, transporting clients, looking for clients, and other non-medical/clinical services not billable to Medi-Cal.
- Support for participants to ensure they understand the process. The current forms are technical and may be difficult for some individuals to understand.

Threats to Implementation

- Substantial vacancies in Behavioral Health and Social Services statewide
 - Lack of applicants for clinicians and social workers
 - Obstacles to offer competitive pay for key positions – clinicians, nurses, social workers
- Deficient number of bed availability for acute psychiatric treatment
- Lack of community housing for prospective new staff moving into the community
- Lack of affordable and low-income housing (for staff and supportive/shared housing)
- Community opposition to homeless shelters/housing
- Lack of local sober living facilities and other residential options to support successful recovery for homeless persons
- Lack of incentives for board & care facilities to operate in California
- Lack of specialized non-profit agencies willing to serve rural areas
- Lack of sustainable, on-going revenues

Cohort 1 Counties

- Cohort 1 Counties have spent months planning for implementation. While there is a high level of concern, we are anxious to get started.

Research Related to Systemic, Racial Justice-Informed Solutions to Shift Care from the Criminal Legal System to the Mental Health Care System and Related Topics

Dr. Sarah Vinson

SOCIAL (IN)JUSTICE & MENTAL HEALTH:

A Framework for the CARE Court Working Group



“A STATE OF WELL-BEING IN WHICH EVERY INDIVIDUAL REALIZES HIS OR HER OWN POTENTIAL, CAN COPE WITH THE NORMAL STRESSES OF LIFE, CAN WORK PRODUCTIVELY AND FRUITFULLY, AND IS ABLE TO MAKE A CONTRIBUTION TO HER OR HIS COMMUNITY”

- W.H.O.

THE
AMERICAN
DREAM





TYPE F PPRE I N

EXPLOITATION

The unequal exchange of one group's labor and energies for another group's advantage and advancement

CULTURAL IMPERIALISM

Establishing the ruling class culture as the norm; othering of groups that are not part of the dominant culture

POWERLESSNESS

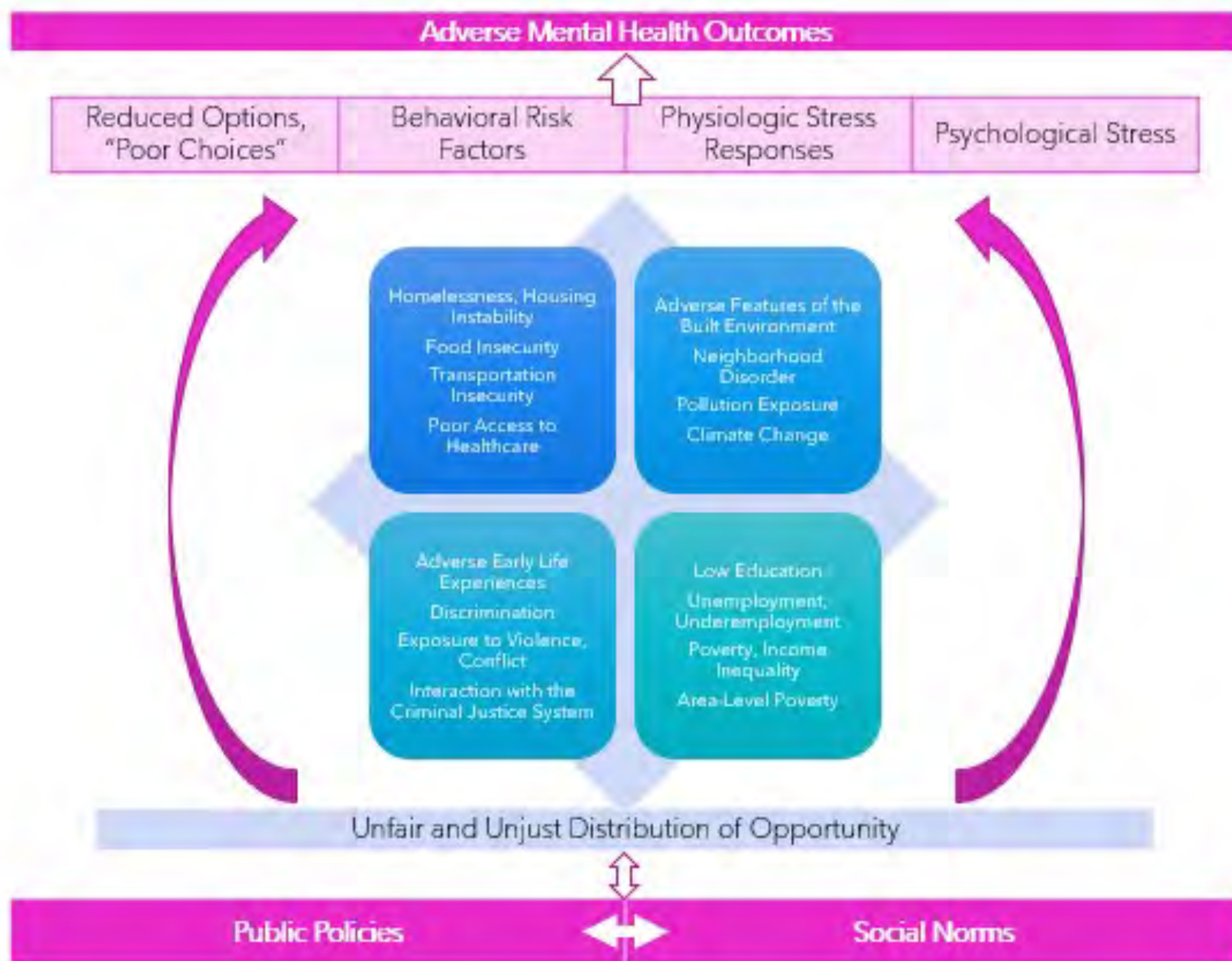
Oppressed groups lack power and are blocked from routes to gaining power

MARGINALIZATION

Expelling specific groups from meaningful participation in society

VIOLENCE

Threats and experiences of physical and structural violence



[Click here to watch](#)



Clark Doll experiments



Share



**IF YOU'RE
TREATED A
CERTAIN KIND OF
WAY, YOU BECOME
A CERTAIN KIND
OF PERSON. IF
THINGS ARE
DESCRIBED TO
YOU AS BEING
REAL, THEY'RE
REAL FOR YOU
WHETHER THEY'RE
REAL OR NOT.**

- James Baldwin

SOCIAL JUSTICE

**“ASSURING THE PROTECTION OF EQUAL
ACCESS TO LIBERTIES, RIGHTS, AND
OPPORTUNITIES, AS WELL AS TAKING
CARE OF THE LEAST ADVANTAGED
MEMBERS OF SOCIETY.”**

-JOHN RAWLS-

PUBLIC M.H. SYSTEM?



ACCESSIBILITY

Physical
Financial
Language



FUNDING

Adequacy
Mechanisms



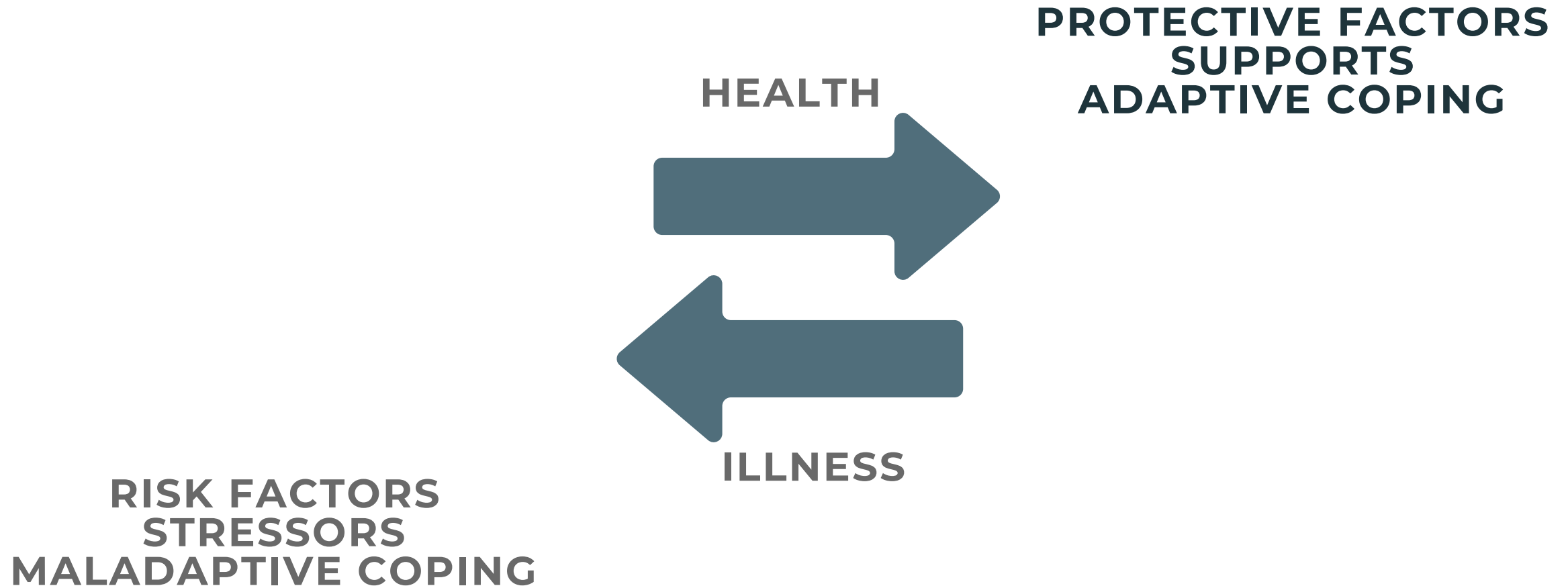
COMPETENCY

Cultural
Structural
Clinical



TIMING

Waitlists
Intake - Treatment



The Mental Illness to Mental Health Continuum

HEIRARCHIES

Mass Incarceration,
Homelessness, Mental Illness and
the Marginalized



SOCIAL CONSIDERATIONS



PRINCIPLES OF ENVIRONMENTAL INJURY LITIGATION



ESSENTIAL ELEMENTS

There are four essential elements in a personal injury lawsuit: duty, breach, causation, and damages. Each element must be proven by the plaintiff to establish liability.



EVIDENCE OF INJURY

Medical records, photographs, and expert testimony are common forms of evidence used to prove the extent and nature of the injury.



LEGAL DETERMINATION

The final step in the litigation process is the legal determination of liability and the calculation of damages.

For more information on environmental injury litigation, contact the Environmental Injury Litigation Center at (800) 555-1234. We provide free consultations and legal representation for victims of environmental harm.

STRUCTURAL TRAUMA

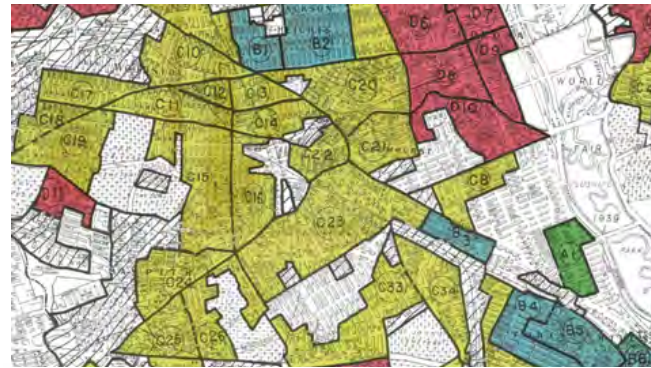
**WHEN SOCIETY'S SYSTEMS AND
STRUCTURES (E.G.- GOVERNMENTS,
ECONOMIES, SAFETY NET SERVICES) AS
THEY ARE CONFIGURED AND
ROUTINELY OPERATE ARE
INSTRUMENTS OF HARM**

MENTAL HEALTH INEQUITIES

**DISPARITIES IN MENTAL HEALTH THAT
ARE A RESULT OF SYSTEMIC,
AVOIDABLE, AND UNJUST SOCIAL AND
ECONOMIC POLICIES AND PRACTICES
THAT CREATE BARRIERS TO
OPPORTUNITY**

HOSPITALS

Inequities arise from the confluence of residential segregation, hospital imperatives to generate revenue, and state policy making.



THE FUTURE IS HERE

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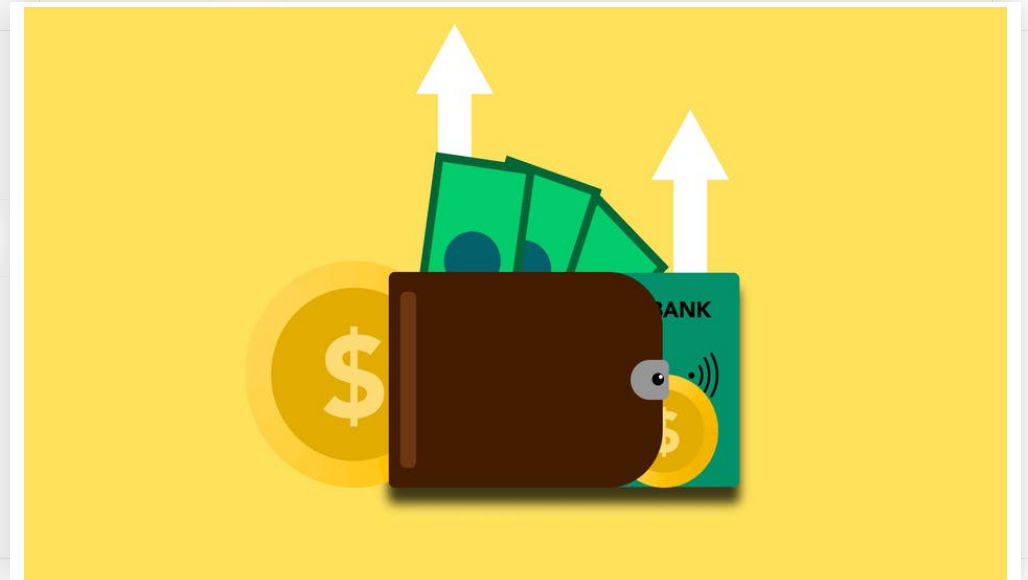
PHYSICIANS

Mismatch of providers vs. the population, with the medical profession reflecting the consequences of economic and social inequality of the U.S. Society at large.

In 2019, only 5% of medical students reported parental incomes in the bottom quintile of U.S. household, versus 51% in the top.

From 2010 - 2016, mean debt rose, but the % zero debt also rose , from 16% to 27%

Most consistent predictor of practice in underserved communities?



PRIVATE HEALTH INSURANCE COVERAGE

Mediator of access concentrated among middle class workers with skilled labor and white collar occupations

Structural Processes such as underinvestment in K-12 education, job-location mismatch, and hiring discrimination produce inequities in overall employment and types by gender, race, ethnicity, immigration status and disability

Black and Latinx people are disproportionately represented in uninsured and those with public insurance



IN 2018,

69%



of Black adults with any mental illness received no treatment

42%



of Black adults with serious mental illness received no treatment

67%



of Latinx adults with any mental illness received no treatment

44%



of Latinx adults with serious mental illness received no treatment

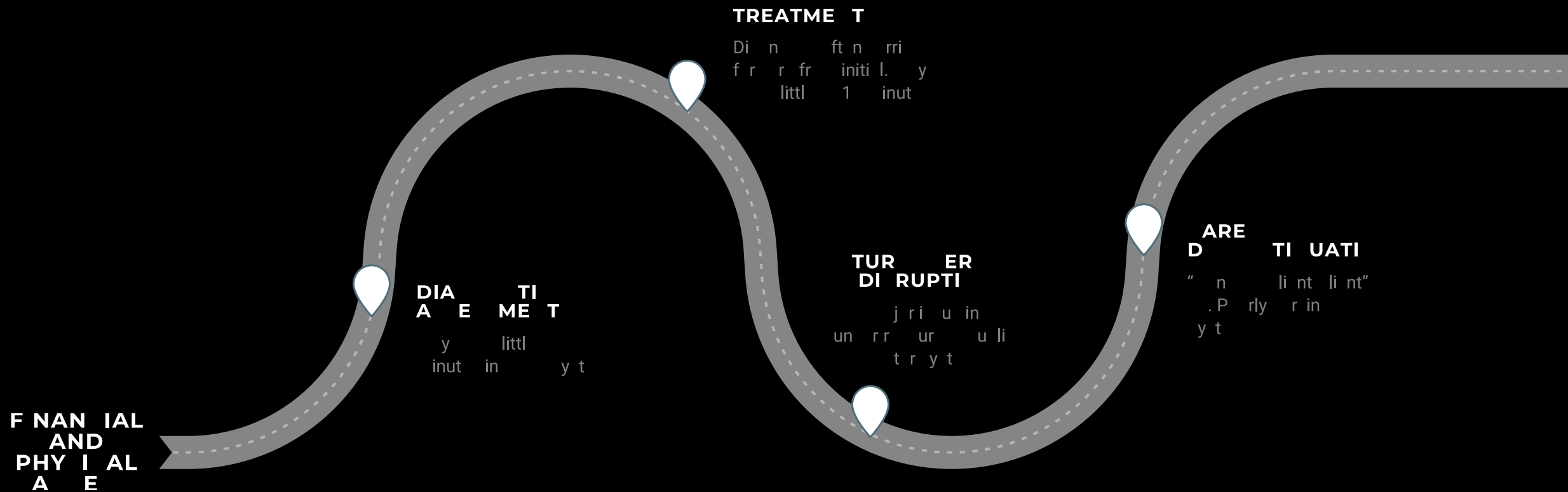


**WHEN BLACKS
WERE ASKED
WHY THEY DO
NOT GET
MENTAL HEALTH
SERVICES...**

**T THEM T
MM NLY TED REA N
F RN T EEK N ARE**

**TWI EA FTEN A
MINIMIZATI N F YMPT M
AND NEARLY FIVE TIME A
FTEN A TI MA**

PU LI MENTAL “HEALTH ARE”





DEFINITIONS BELONG TO THE DEFINERS. NOT THE DEFINED

- Toni Morrison

Crack Babies: The Worst Threat Is Mom Herself

By Douglas J. Besharov

LAST WEEK in this city, Greater Southeast Community Hospital released a 7-week-old baby to her homeless, drug-addicted mother even though the child was at severe risk of pulmonary arrest. The hospital's explanation: "Because [the mother], demanded that the baby be released."

The hospital provided the mother with an apnea monitor to warn her if the baby stopped breathing while asleep, and trained her in CPR. But on the very first night, the mother went out drinking and left the child at a friend's house—without the monitor. Within seven hours, the baby was dead. Like Dooney Waters, the 6 year-old living in his mother's drug den, whose shock-

Children of the Opioid Epidemic

In the midst of a national opioid crisis, mothers addicted to drugs struggle to get off them — for their babies' sake, and their own.

By JENNIFER EGAN MAY 9, 2018



THE NEW DISPARITY - THE EMPATHY, COVERAGE, FUNDING & TRAINING GAPS

Involuntary Hospitalization



Civil Commitment



Experience-Based Fear



Cultural Mistrust

Assisted Outpatient
Treatment

PROPERTY UNDER
24 7 SURVAILENCE



Flashbacks &
Hypervigilance



AUDITORY
HALLUCINATIONS
& PARANOIA

PARALLEL IN CRIMINAL JUSTICE.



- LA K AND
R N PE PLE
MAKE UP THE
MAJORITY F
PE PLE IN JAIL

- F TATE
JUD E ARE
HITE

- M TJUD E
A KN LED E
THE Y TEM I
RA I T

- LA K AND MULTI
RA E PE PLE ARE
DI PR P RTI N
ATELY MMITTED

- F
P Y H L I T
ARE HITE

- HEALTH ARE
PR VIDER
REP RTED LE
EMPATHY F R
THEIR MIN RITY
PATIENT *

LARK HITT R, MALAT J, UR E D, FRIEDEMA A HEZ D T R A D UR E EXPLA ATI F RRA IAL
DI PARITIE I MEDI AL TREATME T J UR AL F HEALTH ARE F R THEP RA D U DER ER ED. 1 ; 1(1): -4

WHEN THE TRAUMA'S NOT "POST"

[Click here to watch](#)



Video shows 10-year-old boy stopping basketball to hide from police car



Share

▶ 🔊 0:00 / 0:37

CC ⚙️ YouTube 🖥️ 🗲

AND NOT COUNTED



IN OUR DSM DIAGNOSES

No Complex PTSD

The limitations of Criteria A for PTSD

No recognition of racial and structural trauma

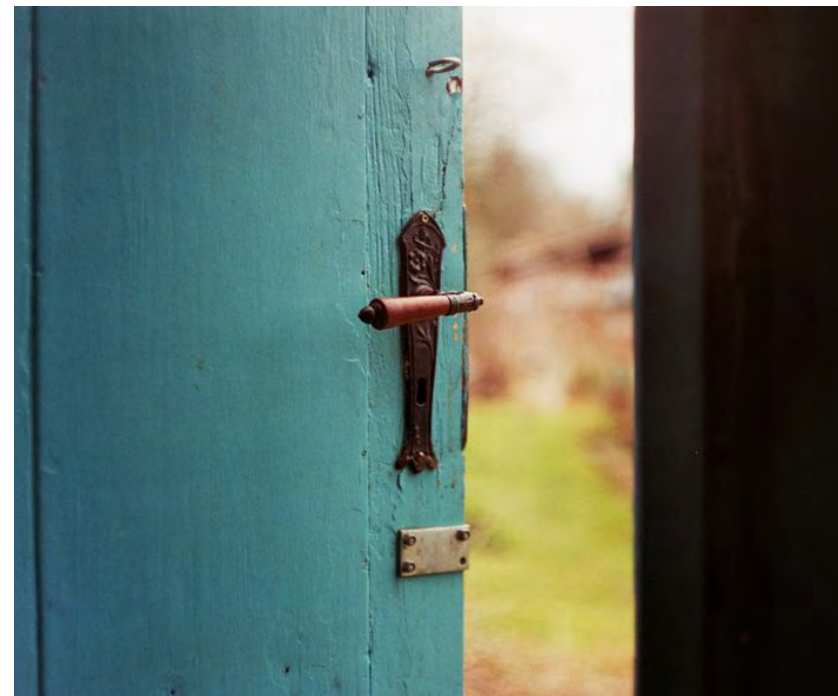
AND NOT COUNTED



IN OUR COMMON INSTRUMENTS

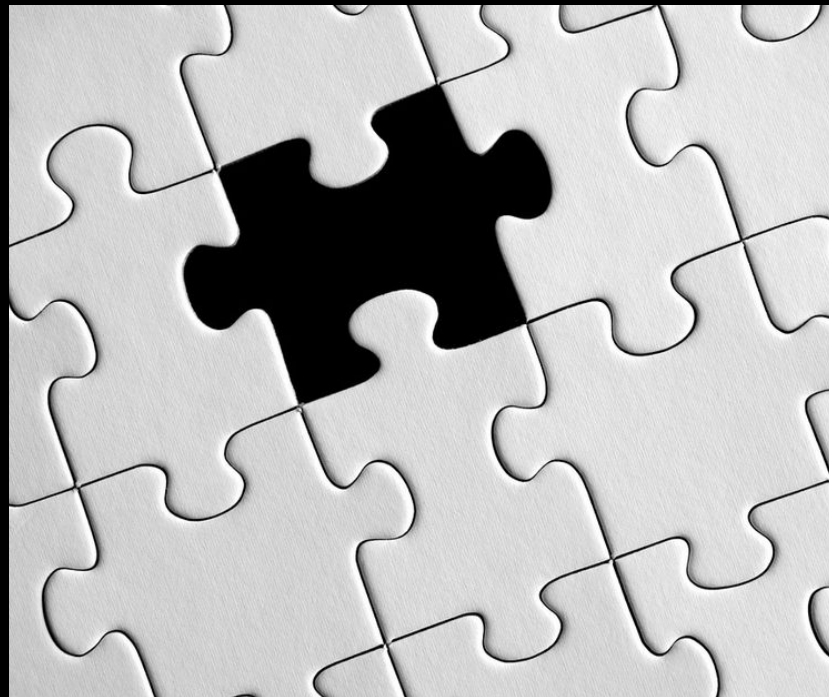
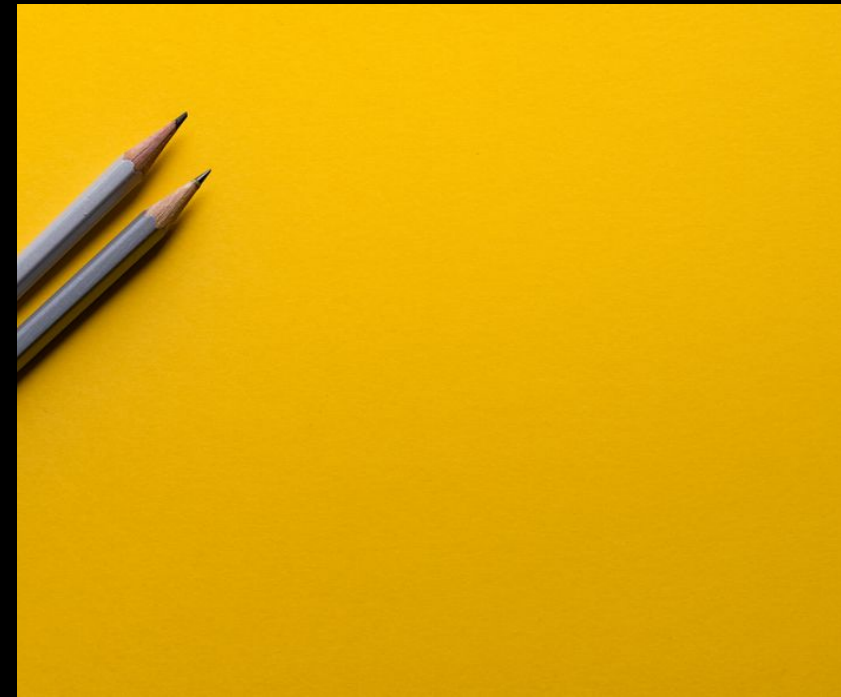
ACE Questionnaire Limitations
Actuarial Risk Assessments
Criminogenic Risk Factors

...IN
CLINIC



IN
COURT

WHAT THE RECORD REFLECTS...OR DOESN'T





**UNDER-COUNTED
TRAUMAS**



**SURFACE
DIAGNOSES**



**POORLY MANAGED
SYMPTOMS**



**STRUCTURAL
BARRIERS**

**TREATMENT REFRACTORY &
NON-COMPLIANT PATIENT?
OR
RECOVERY RESISTANT & (IN)JUST CARE?**

TRUST

DIRECTION, DEVELOPMENT & DIVERSION

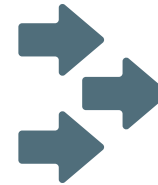
**HOW HAVE SOCIAL INJUSTICE ,
SOCIETAL NARRATIVES, AND
SOCIAL AND SYSTEMIC
MARGINALIZATION IMPACTED...**

The CARE eligible population?

The potential petitioners?

The court system?

The mental healthcare system?



CARE COURT LEADERS

- DEVELOPMENT OF MARGINALIZATION & INEQUITY
- AWARENESS OF PERSONAL BIAS
- GUARDING AGAINST AFFINITY BIAS
- LEVERAGING PRIVILEGE
- ADVOCATING FOR MEANINGFUL REPRESENTATION
- RESPONSE & CONCRETE OUTCOME TRACKING
- AND - ADVOCACY FOR SYSTEMS CHANGE



BECAUSE THERE'S THIS...

**A BAD SYSTEM
WILL BEAT A
GOOD PERSON
EVERY TIME.**

- W. EDWARDS DEMING



**RACIST
SYSTEM**

**+ RACE
'NEUTRAL'
REFORM**

**= RACIST
SYSTEM 2.0**

COURSE CORRECTION

**UNDO NG
INEQU TY**

**APPROACHES THAT
INCREASE M.H. TREATMENT
AND HOUSING
ACCESSIBILITY**

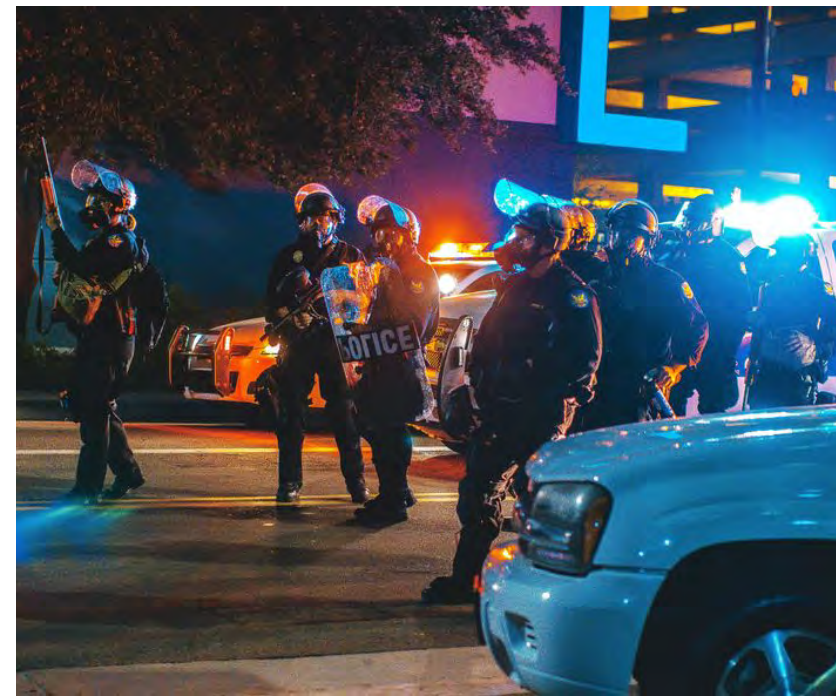
**APPROACHES THAT
ADDRESS THE SOCIAL
DETERMINANTS OF HEALTH
THAT ARE MEDIATED BY
SOCIAL STRUCTURES**

**REBUTTING NARRATIVES
THAT INCLUDE ERASURE OF
CONTEXT, ESSENTIALISM
AND THE DENIAL OF
STRUCTURAL RACISM**



**“IGNORANCE, ALLIED
WITH POWER, IS THE
MOST FEROCIOUS ENEMY
JUSTICE CAN HAVE.”**

- JAMES BALDWIN -





h I u I h I I u I i n n r t . n t h A Tr i i r i n n r h urt

BREAK

Updates on Time Limited Ad Hoc Sub-Groups

Services and Supports – Tracie Riggs and Jodi Nerell

Training, Technical Assistance, and Communication – Susan Holt and Anthony Ruffin

Data Collection, Reporting & Evaluation – Keris Myrick and Beau Hennemann

Supported Decision-Making, Psychiatric Directives, and the Role of the Supporter

Christopher Schneiders
Rayshell Chambers, MPA

CARE Act Working Group Presentation

August 9, 2023

Christopher R. Schnieders

**Brief Overview of Supported Decision Making (SDM) and
Psychiatric Advance Directives (PADs)**

Christopher R. Schnieders, M.A.

Past:

Saks Institute for Mental Health Law, Policy, and Ethics, USC Gould School of Law - 2010-2023

Director of Saks Institute - 2018-2023

Current:

CEO, Schnieders & Co. Consulting LLC

Candidate, Doctorate of Policy, Planning and Development, USC Price School of Policy

CAVEAT: Mostly not original words - sources cited - just not using quotation marks

What are Supported Decision Making (SDM) *and* **Psychiatric Advance Directives (PADs)?**

All too often, the voice and wishes of people with psychiatric disabilities are neglected during real world mental health crisis events.

The basic tenants underlying SDM and PADs are autonomy, self-determination and choice.

What is Supported Decision-Making?

SDM is where people
choose trusted supporters
to help make their own life decisions. *

SDM agreements can be formal or informal

*National Resource Center for Supported Decision-Making. supporteddecisionmaking.org

Consistent, shared language for Supported Decision-Making

SDM = Decision Making is Supported by Chosen
Supporter(s)

Written into CARE Act

Shared Decision Making = Decision Making is Shared
Valid, not SDM, not in CARE Act

Supportive Decision Making = Decision Making is
Supportive (?)

not SDM, not in CARE Act

International Context

Supported Decision-Making is a relatively new paradigm in the U.S. and currently figures prominently context of the principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). In particular, CRPD Article 12 affirms that persons with disabilities have the human right to recognition as persons before the law.

States Parties to the CRPD must recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. States must take appropriate measures to provide access by persons with disabilities to the supports they may require in exercising their legal capacity, such as through SDM.

Under Article 12, States Parties are to enact measures that relate to the exercise of legal capacity in accordance with international human rights law. These safeguards are to ensure that the exercise of legal capacity respects the rights, will, and preferences of the person, and are tailored to the person's circumstances. *

* Schnieders, C., Saks, E., Martinis, J., & Blanck, P. (2021). Psychiatric Advance Directives and Supported Decision-Making: Preliminary Developments and Pilot Studies in California. In M. Stein, F. Mahomed, V. Patel, & C. Sunkel (Eds.), *Mental Health, Legal Capacity, and Human Rights* (pp. 288-301). Cambridge: Cambridge University Press.
doi:10.1017/9781108979016.022

Saks Institute for Mental Health Law, Policy and Ethics

Supported Decision-Making Pilot Study

In 2016, the Saks Institute - in collaboration with the Burton Blatt Institute at Syracuse University - began work to develop an SDM pilot research study focused on people with psychiatric disabilities, specifically people with schizophrenia and bipolar disorder who have experienced psychosis.

At three university sites in California and one in New York, the research teams partnered with people with psychiatric disabilities to educate and help participants create written SDM plans identifying areas of their lives where they want support making decisions - including the type of support they want, who will provide it, and how.

Saks Institute for Mental Health Law, Policy and Ethics

Supported Decision-Making Pilot Study

We interviewed individuals and organizations that have used SDM and/or undertaken SDM projects, including the American Civil Liberties Union, the Autistic Self Advocacy Network, the Center for Public Representation, First in Families North Carolina, the American Bar Association and others. These interviews helped us learn about their experiences, methodologies and challenges.

Building upon that research and significant efforts in the IDD/DD communities, we created a new suite of tools, materials, and study protocols. Our hope was to help study participants increase their abilities and opportunities to make their own decisions and direct their own lives. *

Spring 2017 - Saks Institute Symposium “Supported Decision-Making: Giving Mental Health a Voice”

* Schnieders, C. (2019). Supported decision-making and people with psychiatric disabilities: Pioneering research at California’s Saks Institute. *Impact* 32(1), 40–41
publications.ici.umn.edu/impact/32-1/supported-decision-making-and-people-with-psychiatric-disabilities-pioneering-research-at-californias-saks-institute

* Schnieders, C., Saks, E., Martinis, J., & Blanck, P. (2021). Psychiatric Advance Directives and Supported Decision-Making: Preliminary Developments and Pilot Studies in California. In M. Stein, F. Mahomed, V. Patel, & C. Sunkel (Eds.), *Mental Health, Legal Capacity, and Human Rights* (pp. 288-301). Cambridge: Cambridge University Press. doi:10.1017/9781108979016.022

*SDM Pilot Study Funders: Battery Powered SF and Sidney R. Baer Jr. Foundation

What are Psychiatric Advance Directives?

A PAD is legal rights document
that records a person's preferences for future mental health treatment
and
allows a health proxy to interpret those preferences during a crisis.*

* National Resource Center on Psychiatric Advance Directives. nrc.pad.org

International Context

2023: Lyon, Paris and Marseille, France

Study/Paper: “Psychiatric advance directives facilitated by peer workers among people with mental illness: economic evaluation of a randomized controlled trial (DAiP study)” *

Aims: We aimed to assess the cost-effectiveness of psychiatric advance directives (PAD) facilitated by peer workers (PW-PAD) in the management of patients with mental disorders in France.

Conclusion: PW-PAD was strictly dominant, that is, less expensive and more effective compared with usual care for people living with mental illness.

Saks Institute and MHSOAC

Innovation Project Planning: PADs as a Form of SDM

Late 2019 through 2021, the Saks Institute engaged with California's Mental Health Services Oversight and Accountability Commission (MHSOAC) in a multi-county innovation planning project in California to pilot programs and test the feasibility of using PADs within the SDM paradigm. The project is a first-of-its-kind effort to explore the efficacy of the PADs/SDM paradigm across behavioral health county systems in California. The goal is to develop a county-level and longitudinal PADs/SDM project to improve community mental health services for people with psychiatric disabilities at risk of involuntary care, criminal justice involvement, and involuntary hospitalization.*

[2019 Saks Institute Spring Symposium "Working and Living with Mental Illness"](#)

[2021 Saks Institute Spring Symposium: "Psychiatric Advance Directives and the Importance of Choice"](#)

* Schnieders, C., Saks, E., Martinis, J., & Blanck, P. (2021). Psychiatric Advance Directives and Supported Decision-Making: Preliminary Developments and Pilot Studies in California. In M. Stein, F. Mahomed, V. Patel, & C. Sunkel (Eds.), *Mental Health, Legal Capacity, and Human Rights* (pp. 288-301). Cambridge: Cambridge University Press. doi:10.1017/9781108979016.022

A Few Things to Consider

Working Together: Collaboration, information sharing and continuity of care

In project interviews, the counties reported that one barrier to adoption of PADs/SDM was the “silo” nature of service systems and providers. In such systems, public and private providers often do not communicate or collaborate most effectively in the “voice” of the individual. Each provider may have operating policies and procedures that conflict in practice with those of other providers. In such systems, PADs typically are of limited use because providers and first responders may not have (or may have conflicting) policies or practices to encourage people to create them, or mechanisms to recognize and respect them. *

The Importance of Chosen Supporter(s) and Proxy Decision Makers

* Schnieders, C., Saks, E., Martinis, J., & Blanck, P. (2021). Psychiatric Advance Directives and Supported Decision-Making: Preliminary Developments and Pilot Studies in California. In M. Stein, F. Mahomed, V. Patel, & C. Sunkel (Eds.), *Mental Health, Legal Capacity, and Human Rights* (pp. 288-301). Cambridge: Cambridge University Press. doi:10.1017/9781108979016.022

Last Thing

“Not being allowed to make decisions for oneself is very degrading, painful, and disempowering. Patient choice is important even if the patient is impaired. Or even if we think he or she is making an obviously wrong decision. We allow people to make foolish or unwise decisions all the time.

Indeed, force is an unstable solution. If we encourage the patient to make her own decision, she is likely to be more committed going forward.” *

- Elyn Saks

*Saks, E. R. (2019). The power of making decisions. Impact 32(1), 42
publications.ici.umn.edu/impact/32-1/the-power-of-making-decisions

The Role of Peer Supporter with PADs

Presented by Rayshell Chambers,
MPA

Painted Brain: Mission & Role in PADS Advocacy

- Painted Brain (PB) is a nonprofit founded in 2005 that creates lasting community-based solutions to mental health challenges and the impact of social injustice through arts, advocacy, and enterprise.
- **Over the last 3 years**, PB has been the leading peer and behavioral health advocacy voice in PADS education reaching hundreds of clients/consumers/family members as well as various other stakeholders including law enforcement, Counties Behavioral health departments, academia and elected officials.
- PB has developed a webpage dedicated to PADS education as well as created various educational videos, Frequently Asked Questions pamphlets and other materials on the topic.



What is a Psychiatric Advance Directive (PAD)?

➤ Overview & Description

- A Psychiatric Advance Directive (PAD) is a self-directed legal tool that enforces the rights of the consumer during crisis.
- Puts the voice of the peer at the forefront of their treatment.
- It is used to plan for the possibility that someone may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness.
- It allows a person in a mental health crisis to retain their decision-making capacity by choosing trusted agents to help advocate for their choices.

Potential Sections of a PAD

Current Medical Conditions	*Psychoactive Medication
Treatment Preferences	*Preferences for Emergency Treatment
Accessibility	*Agents & Supporters
Crisis Team Support	*Law Enforcement & Crisis Workers
Accessibility	Disabilities
Treatment Preferences	Directive if I am hospitalized
Treatment Preferences	Preferences Regarding Treatment Facilities
Current Medical Conditions	Critical physical medical conditions
Current Medical Conditions	Gender Affirming Treatment
Current Medical Conditions	Reproductive Health
Recovery and Reentry Supports	Housing
Recovery and Reentry Supports	Employment
Recovery and Reentry Supports	Education

About Me: My Story & Why PADs

- Began utilizing the public mental health system at 6 years old due to traumatic life events.
- Hospitalized 4 times beginning at the age of 14 and currently utilizing services for severe mental illness.
- During my hospitalizations, doctors had no clue what medicines made me suicidal or just didn't work; nor did I have many people I trusted to call my school or work.
- I often worry about what will happen if I need to be hospitalized again.
- A Psychiatric Advance Directive will provide legal protection for my voice during crisis treatment.

What are Peers Doing Relative to PADs?

Milestones with PADs:

- In partnership with the Copeland Center, PB developed and hosts a PADS National Peer Support Network to organize and engage peers across the US to gain best practices, share resources and mobilize relative to peers providing PADS education and document development.
- In partnership with California Association of Mental Health Peer Run Organizations (CAMPHRO), PB is contracted through the PADS Innovation project with Contra Costa, Fresno, Mariposa, Monterey, Orange, Shasta, and Tri-City.

Peer Voice in Innovations project consists of:

- Peers supporting with developing a standardized PAD template that will be turned into an online and interactive app (the PAD technology platform), with a PDF version available for situations that do not allow for online access
- Legislative and policy advocacy to create a legal structure to recognize PADs
- Evaluate development and adoption of PADs, including ease of use and understanding of PADs
- Create a sustainable and easily reproducible approach that can be used across California

SB 803 and The Peer Support Specialist

- Under SB 803, County Behavioral Health departments will seek providers of Behavioral Health Prevention Education Services and Self-Help/Peer Services under new procedure codes (H0025 & H0038).
- **Peer Support Services include the following service components:**
 - **Educational Skill Building Groups:** socialization, recovery, self-sufficiency, self-advocacy, development of natural supports, and maintenance of skills learned in other support services.
 - **Engagement support:** encourage and support beneficiaries to participate in behavioral health treatment.
 - **Therapeutic Activity:** advocacy on behalf of the beneficiary, promotion of self-advocacy, resource navigation, and collaboration with the beneficiaries and others providing care or support to the beneficiary, family members, or significant support persons.

SB 803 and The Peer Support Specialist

- In working with Peer Support Specialists or in peer support groups, clients can work on crisis planning (WRAP, PAD, other) with other peers or those who have already developed plans.
- Peer Support is always a critical and valuable resource.
- Peers can also work with clients in selecting an agent and help them develop a larger circle of support.
- Aside from the PAD and the WRAP crisis plan, a supporter and supporters can provide a circle of care when you are going through a crisis.

PADS & CARE Court: Consumer Voice and Choice is First!

PADS Provides:

- Protection
- Provide information about the people who may refer.
- **For example:** My spouse, X, has been physically, sexually, verbally and emotionally abusive in the past and therefore cannot be trusted to act in good faith for any CARE Court referral.
- Designate supporter(s)
- Provide preferences regarding potential supporters.
- **For example:** I have a history of trauma. It is important that my supporter identifies as female.
- If possible, my supporter should have lived experience with involuntary hospitalization. It is important for me to know that my supporter understands the involuntary hospitalization experience.

- State who should not be a supporter and why.
- Psychoactive medication not wanted and why.
- Design specific sections to address CARE Court.
- Draft individualized PAD language to address CARE Court issues.
- Advocacy
- Housing accommodations and supports
- Desired services, and why.
- Things that do not work/have not worked in the past, and why.

Laurie Hallmark, 2023 PADS Overview to DRC

Discussion of Development of CARE Act Communication Tools

Working Group Members

Closing Thoughts

*Stephanie Welch, MSW, Deputy Secretary of
Behavioral Health, CalHHS*

Public Comment

Public Comment will be taken on any item on the agenda

There are 3 ways to make comments:

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

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

Adjourn and Thank you!