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**Mental Health Commission
Quality of Care Committee Meeting
Thursday, June 17, 2021, 3:30-5:30 pm**

Via: Zoom Teleconference:

<https://cchealth.zoom.us/j/6094136195>

Meeting number: 609 413 6195

Join by phone:

1 646 518 9805 US

Access code: 609 413 6195

AGENDA

- I. Call to order/Introductions**
- II. Public comments**
- III. Commissioner comments**
- IV. Chair comments**
- V. APPROVE minutes from May 20, 2021 Quality of Care meeting.**
- VI. SELECT Adult sites to visit August 2021 through March 2022.**
- VII. DISCUSS process of assigning sites to Commissioners.**
- VIII. DETERMINE final steps with HUME Center visit and report.**
- IX. DISCUSS plan to move forward “Housing that Heals” agenda.**
- X. REVIEW “Alternative Destinations,” new options in addition to Psych Emergency Services (PES), primarily recommended by the Crisis Intervention Rapid Improvement Event 3 Design Team.**
- XI. Adjourn**



The Contra Costa County Mental Health Commission is appointed by the Board of Supervisors to advise them on all matters related to the county's mental health system, in accordance with mandates set forth in the California State Welfare & Institutions Code, Sections 5604 (a)(1)-5605.5. Any comments or recommendations made by the Mental Health Commission or its individual members do not represent the official position of the county or any of its officers. The Commission is pleased to make special accommodations, if needed, please call ahead at (925) 313-9553 to arrange.

Hume Center Site Interview Report (draft)

Authored by the Contra Costa County Mental Health Commission

Quality of Care Committee Site Visit Program Test

Date of Interviews: April 23, 2021

Date of report: May 27, 2021

Reviewed Programs: Contra Costa County Concord Out-patient and Partial-Outpatient Programs

Interviewers: Commissioners Laura Griffin, Leslie May and Barbara Serwin

Version: This version incorporates comments from the Program Director of Hume Center from her review of a first draft of the report. The next draft will incorporate answers to outstanding questions and will be the final draft.

Notes:

- **This report is the result of a Site Visit Program test conducted in April – May, 2021. Hume Center was the test site.**
- **Hume was visited virtually during COVID when visits to facilities were not permitted. Instead of a physical site visit, Commissioners interviewed clients and staff via Zoom.**

I. Brief Summary

Hume Center in Contra Costa County serves as a bridge between in and out-patient hospitalization. People go to Hume instead of hospitalization or as a step down. The people treated by Hume are truly those in greatest need: Those who are gravely mentally ill, possibly indigent, and with no other access to services.

Hume's Partial Hospitalization Program (PHP) can serve up to 20 adults, who are Medicare recipients. Since it is a PHP where individuals reside in the community, they do not have beds.

The PHP is supervised by a Licensed Psychologist and is staffed daily by doctoral interns, and graduate level practicum students. PHP also employs a Psychiatrist, a psychiatric Nurse Practitioner, a Registered Nurse, and receives administrative support from the clinic's operations assistant.

One other item of note is the extent to which Hume embraced working with the Quality of Care Committee of the Mental Health Commission throughout development of the Site Visit Program starting in Spring of 2020. When the design phase began, Hume immediately volunteered to be the test site of the new Site Visit. Through-out the test, Hume was enthusiastic, open and supportive and its participation was invaluable.

II. Consumer Perspective

Number and type of interviewees: 5 female adults

Strengths

1. Hume patients have considerably lengthy stays e.g. 6 months for more thorough treatment. According to one patient: *“At John Muir you are limited to four weeks then they cut you off. I needed something longer term until I was well. I can sustain my progress with the Hume program.”*
2. Overall, patients reported that they were getting better. According to one patient: *“Yes. I was able to prepare for an upcoming court date – being in front of the judge, navigating the process. I was nervous. I’m now at peace – not anxious like a “9 or 10” (scale) constantly – I’m more like a “1 – 2”. No more (very few) night terrors.”*
3. Patients most commonly mentioned the following services as strengths: One-on-therapy; group therapy; psycho-education; classes on mindfulness, breathing exercises and art therapy; making friends and a sense of community. According to one client: *“They care. My counselor wouldn’t ask me to do anything that he wouldn’t do himself. Amazing suggestions. The therapists give a lot of knowledge. We have peer group therapy to advise each other. I take more what they say. They are high-functioning and can give advice.”*
4. Except for one patient, patients reported that staff asked for input re: their services.
5. Patients were in agreement that the program provides social opportunities and therapeutic activities.
6. Overall, patients are happy with most aspects of medication management.
7. Overall, patients have easy time getting an appointment.
8. Patients are able to read and understand the formal documentation at intake, e.g. HIPPA document.
9. Patients know their rights at Hume, such as confidentiality.
10. All patients knew what a patient’s rights advocate is and how to contact one.

11. Hume allows clients to see their external providers for therapy and medication management. According to one client: *“The program is so much better than John Muir. I’ve been in John Muir, which is medication-focused; John Muir wanted to control meds and wouldn’t let me see an outside doctor. This program (Hume) lets me see my normal psychiatrist and therapist with who I have the bonds.”*
12. Hume has a grievance process that seems to work for clients. Although one client found the documentation off-putting, four patients used the grievance process to successfully resolve their issue.

Challenges

1. Hume clients are pre-dominantly indigent, middle-age, Caucasian and Black females – a population over-represented across all mental health sub-populations. However, at the time of the Hume site interviews date, Hume had only one male client and the rest were females. The only non-Caucasian was a Black female client who said: *“I am the only African American in the program. There are no African American men in the program, no Hispanic, no Native American, no Middle Eastern in the program. They are all Caucasian women and one man in the program.”* Attaining a more gender and racially/ethnically diverse client population is a challenge. While the Hume board of directors is diverse, it is not necessarily reflective of all of the community that it serves.

Note: According to the Program Director, while Hume has had more diversity in the past -- more men and more ethnic minorities, such as African Americans, Asians, Hispanics and Indigenous People), the current makeup of the patient population doesn’t truly reflect that. This is mainly because the census is low and therefore it is not a representative sample of Hume’s usual population. They think it is a function of their limited ability to outreach to the community in person and the technology barriers that people are facing to access services due to COVID. The words of the client who expressed concern about diversity are powerful and speak to her experience. It has been challenging for Hume to outreach during this period, and as a team, Hume staff is working together to address these issues.

2. One patient described the place as much too small and too dark. This sentiment was echoed by staff.
3. While one client was provided education for working with the legal system, and one was told about resources, other clients didn’t engage this service of Hume. One person was never asked if she needed other services. Hume can provide an important benefit by sharing resources weekly with everyone.
4. Three clients did not have an advanced directive. One patient got hers elsewhere. A fifth patient didn’t know what an advanced directive is.

5. One client was concerned about security. She believes that there are no security checks and told a story about a man threatening to kill someone a year and a half ago. Note: According to the Program Director, in the past few weeks, Hume has installed a doorbell at the main entrance so that only staff, visitors and clients can enter. This has helped Hume control who has access to their waiting room to protect patient safety and privacy.

Other Observations

1. Most patients believe that staff help them use their personal strengths, skills, and capabilities in recovery.
2. A few patients believe that the services are adjusted to their specific needs, e.g. ethnicity. However, one patient pointed out that the lack of diversity did not meet her needs.
3. For patients with a medical issue(s), the issue was accounted for in their treatment program.
4. Although Hume has a peer provider (a SPIRIT intern), patients reported that they didn't have one.
5. People feel safe in the neighborhood. Three clients use the van transportation – Hume could publicize this for other people too. Note: According to the Program Director, prior to COVID, transportation was the biggest barrier to attending service. Hume has therefore been providing transportation to PHP patients since the inception of their program.
6. Only one patient is a care-giver for her mother, who has mental illness, and Hume gives her space to process her feelings around being the care-giver.
7. One client spoke of the need for everyone to be required to attend group therapy every day. She likes Hume for its social opportunities and feels that lack of consistent attendance compromised her group therapy experience.

Client Magic Wishes

- Two clients emphasized their desire to meet in person. Zoom was helpful, said one, but not as beneficial.
- One client wished for a spacious, sunny and light facility.
- One client wished for diversity.
- One client wished for everyone to be required to attend group therapy every day.

III. Staff Perspective

Number and type of interviewees:

- 1 Psychology doctoral intern
- 1 Nurse Practitioner
- 1 Program Director

Strengths

1. The program staff works very well together and there is respect and a strong sense of community.
2. Staff members feel fulfilled by their work.
3. Clients can refer themselves to Hume, which seems like a significant strength in an environment of highly controlled access to beds. Clients can also be referred to Hume by Access Line, John Muir, social workers, family members, case managers
4. Hume emphasizes measuring the progress of its clients through the evaluation and tracking components of its programs.
5. Hume employs evidence-based-practices in several therapeutic areas.
6. Hume has a formalized grievance policy and has a compliance department to review grievances.

Challenges

1. Hume is working significantly below capacity (7 to 8 patients recently versus 20 capacity). Despite awareness efforts, including a lot of presentations e.g. to board and cares and other providers, Hume's PHP is not well enough known.
2. COVID-related:
 - Hume has experienced lack of access to technology.
 - Hume clients have experienced isolation and less access to services.
 - If clients are triggered in the moment, staff is unable to provide intimate face-to-face contact with that client.
 - Staff do not feel that Tele-health is as effective as in-person and it has taken a long time to get into a new routine.
 - Clients must be trained how to use the smart phone and tablet/lap top to communicate via Zoom
3. Two staff members were not trained on incident reporting.

Other Observations

1. In addition to providing treatment, Hume is a teaching and hands-on training facility and a research program. This seems unique outside of a teaching hospital affiliated with an academic or research institution. It would be instructive to know Hume's philosophy and how the treatment of clients is prioritized. On the Hume website home page, these core functions are presented with equal weight. As a result, it is not clear whether treatment is the top priority.
2. While limited in the use of peer supports due to payment by Medicare and Medicaid, Hume does host a SPIRIT intern each year.
3. Hume uses a master treatment plan approach, with check-ins on client goals and progress at least every two weeks.

Program Improvement Needs

1. PHP needs case management e.g. for funding, referral connection and housing resources. This lack of a basic need gets in the way of treatment. Other Hume programs than PHP, however, can provide case management services.
2. Hume needs access to technology as long as Telehealth is being used.
3. Hume needs more opportunities for staff and volunteers to help with outreach.

Staff Magic Wand Wishes

1. Hume would accept anyone with any type of diagnosis regardless of their insurance.
2. Hume would have more patients – its census is low. According to one staff member: *"There are people out there that need help."*
3. Hume needs a larger facility with open windows and fresh air. Plastic dividers are needed for COVID-distancing. Note: Per the Program Director, because clients have been meeting virtually since COVID began, they have not yet seen that Hume has changed the room where the PHP will resume in-person services. Once services resume, the main room that PHP will utilize for daily services will now have better ventilation, light, and a large space.

IV. Recommended Areas for Action Plans

This section lists suggested areas of improvement, including some ideas for strategies.

Training on Incident Reporting

- Ensure that all employees are trained on incident reporting. Note: Per the Program Director, based on our site visit recommendations, Hume will increase how often this training is provided to incoming staff and trainees.

Raise Awareness of Hume Client Treatment Programs

- Consider more social media presence, perhaps through volunteer or SPIRIT support.
- Consider what the Hume web site communicates. Treatment is not front and center -- the web-site home page is not client-focused and client-friendly. Hume is a multi-faceted organization and needs multiple pathways into its web-based information. However, the web-site home page is what needs to greet whoever approaches the site. Note: The Program Director says that Hume is working on a plan to update the website in order make it more client treatment oriented.
- Ensure that program presentations are likewise focused on the client and treatment.
- Consider ways to leverage staff and volunteers in the outreach effort; this may require additional funding. While current trainees have taken on this challenge in the last couple of weeks in addition to their regular responsibilities, this should not be a long term solution and could lead to staff burn-out and decreased quality of services.

Technology Access and Training

- Consider prioritizing obtaining and managing technology for essential Tele-health and for continued delivery of online classes, groups and therapies that worked well during COVID and remain a viable option. Note: As per the Program Director, technology access will continue to be a focus as Hume reconsiders how to deliver services and provide a hybrid program of in-person and virtual services.
- Consider developing a training program to teach clients of all ages to use the smart phones, tablets and laptops necessary for therapeutic purposes and case management when in-person therapy or services are not accessible. Note: Per the Program Director, last year, because of shelter in place restrictions Hume developed a training manual individualized to each patient, which was given to them with a loaned a smart phone. The training was done by phone due to COVID restrictions. This year, however, they will definitely consider in-person training.



Housing That Heals: A Search for a Place Like Home for Families Like Ours

By Teresa Pasquini and Lauren Rettagliata

May 2020



*Housing That Heals:
A Search for a Place Like Home for Families Like Ours*

Special acknowledgement to Lauren's granddaughter, Olivia, at age 6, for creating our *Housing That Heals* logo. She worked on it for three days and is enormously proud of her lettering and coloring, stating that she "had developed a special technique!" When asked why there was a dog in the picture, she kindly replied, "It's a cat! I put it there because everyone needs someone to love." ❤️💜❤️🤎❤️





“When hearts are broken, minds are open.”

Erika Jensen, Deputy Health Director, Contra Costa County

What would drive two moms to go on a 3,170-mile journey looking for the housing options available to the most vulnerable people in California—those with a serious mental illness?

The answer is that for decades, we and thousands of families have been trying to build housing that will save our loved ones from living on the streets, jails, and grim care homes with untrained staff.

Teresa Pasquini and Lauren Rettagliata on the Road in 2019





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A Mom's Mission **By Lauren Rettagliata**

There are many people who think that hell is a place for the damned—I am not one of them. I am consumed by the fires of hell when I see my child being harmed and am powerless to stop it. In 1975, my oldest son was diagnosed with Autism at Stanford Hospital. The doctors explained to us that it was still classified as Childhood Schizophrenia. When we sought early childhood intervention for my son in 1975, we were told that he did not qualify for admittance to the programs offered in the school districts, and he was to attend the Agnew State School in Santa Clara, California. My husband and I went for a visit and recoiled in horror... over our dead bodies would our son be institutionalized! We scoured the nation for a system that allowed our precious son to stay in his community. We found this in Northwest Harris County, Texas; they had an Early Childhood System that accepted children most other systems deemed uneducable.

In the early 1980s, Texas was still in the process of opening its state facilities for those with “Mental Health and Mental Retardation.” We made new friendships with families who also had children in “Special Education.” I became a Board Member of the Association for Retarded Citizens of Northwest Harris County.

Children and adults with serious mental illnesses were being brought back into the community from state institutions, and group homes were opening to house them. Entrepreneurs realized that squeezing many bodies into a small house could generate a decent income. The problem was that most of these entrepreneurs knew little about the services and supports the people they were taking into their group homes needed. As a result, many individuals were living in tortuous and abusive situations, being raped, beaten, and abandoned behind locked doors in their own

communities. Men, women, and even children were placed in these horrific group homes.

As a member of my local ARC (we were called the “mad mommies”), we stepped up and declared that there is a better way. We quickly learned the ropes of acquiring state funding to build a better group home model that provided treatment and care; not just three meals per day and a bed. We educated the state and county government administrators about the caregivers’ need to have a deep understanding of the person they were caring for. Our local ARC formed a nonprofit, Reach Unlimited, that would receive the federal, state, and local funding needed to build and operate housing with the supported services. Reach Unlimited brought dignity and respect to every resident who resided in their new home. Today, Reach Unlimited has grown to provide more than residential services; it now has six group homes and provides supported employment, a learning activity center, and home and community support services. Sadly, group homes run sheerly for profit still exist, but now families have a choice and state and local administrators have better options.

Our family moved to Colorado in 1990. This new community was facing the impossible situation of having the YWCA’s Women & Children Crisis Shelter shut down if they could not generate funding for a costly renovation. The turnaround time for this was a brutal eighteen months. With a dedicated Executive Director, Diane Porter, I accepted the challenge and used the grant writing skills I acquired in Texas to help deliver the funding and architectural planning needed to transform the historical building into a state of the art Crisis Shelter.

The lesson I learned from that experience was that determination can transform what was initially seen as impossible into the possible.



*Housing That Heals:
A Search for a Place Like Home for Families Like Ours*

In 1997, we moved back to California to care for our parents. This is when our youngest of four sons had his first psychotic break. Our health care provider immediately recognized that our son had Schizophrenia and placed him in a treatment facility. Our son refused to stay in treatment. He also suffers from a condition known as Anosognosia, a lack of insight which impairs his ability to understand and perceive the severity of his illness. He has attempted suicide multiple times and threatened harm to others. He has fallen into homelessness and addiction and has lived in flea and rat infested room and board homes. My son perceives himself to be unworthy of living in decent surroundings and instead believes that a rundown single room, jail, or being homeless on

the street is where he belongs. His psychosis has trapped him in a world where he sees his only relief as overdosing on drugs and alcohol.

My son needs intensive treatment and a decent place to live so that he can get up each morning and experience a life worth living. That is why I have traveled over 3,000 miles in California studying what has been built to house those who suffer with a serious mental illness. For far too long, we have attended countless planning meetings but have yet to witness the execution of plans that will end the human log jam for those who need more than *Housing First*.

It is now time for Housing That Heals.

A Broken Heart Drives My Mission for Housing That Heals

By Teresa Pasquini, Mom

I am a recovering, angry mom on a mission with a trauma tattoo on my heart. I am willing to partner with anyone who will help me shatter the status quo that is forcing too many families like mine to suffer needlessly. I am grateful that Lauren Rettagliata invited me to join her on a journey in search for "Housing That Heals." Like Lauren, I am just a mom who became an accidental activist in order to save my son's life.

I am the proud mom of Danny, who has been living heroically with schizoaffective disorder since the age of 16. Danny had been diagnosed early upon his first break. He had a psychiatrist, psychologist, and pediatrician all working in sync with our family. He was in treatment, on meds, in supported education, received a high school diploma and had a job. Danny was in a peer support group, and my husband and I were in a parenting support group to learn everything we could to help our son. We thought we had managed his care.

On his 18th birthday, Danny fell off the edge of a cliff and into the black hole of the adult system of care. After 18 years of Lanterman Petris Short (LPS) Conservatorships and a lot of suffering, he is only now beginning to show some promise of long-term stability. But, he is still conserved; and he is doing well enough that the conservatorship may not continue. I am afraid that he will, once again, fall into the black hole of the adult system of care for those with the most serious mental illnesses and not be able to find his way back out.

Currently, I spend all of my free time focused on advocating for a full continuum of psychiatric care that includes all levels of Housing That Heals.

That continuum must include Institutions for Mental Diseases (IMDs) and Adult Residential Facilities (ARFs) for those who cannot survive in supported independent living and do not deserve to be housed in a jail pod or a cardboard tent.



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I am a mom on a mission to ensure that there will be a place for my son to live in health, safety, and dignity when I am no longer here. And, I want that for all people who live heroically with serious brain disorders and mental illness.

I am a former Contra Costa County Mental Health Commissioner, serving for nine years from 2006-2015. I was also a founding member of a Behavioral Health Care Partnership that began in 2009 at Contra Costa Regional Center, our county's public hospital. It was one of the first patient and family partnerships in the nation that focused on Psychiatric units; the forgotten units with forgotten patients. It is this work that taught me the importance of partnering with patients, families, and the staff who serve both.

I have traveled extensively telling my family story in a variety of forums, including the Institute of Healthcare Improvement, a Grand Rounds at the University of Michigan with our Chief of Psychiatry, an event at the National Quality Forum with a Contra Costa Sheriff Deputy, and a media event on Capitol Hill in 2015. I was one of three family members from California who told our stories of failed first care that ended with tragic consequences for all three families. It is hard to capture the depth of despair that my family and so many others have experienced. However, because of luck, heroics, and partnerships, my son is living safe and free today in the community.

My purpose for taking this journey is to start a crucial conversation that will not leave my son uncounted.

This is a moment in time when our collective community purpose must be fluid, flexible, adaptable, and ever present when people are their most vulnerable. And, vulnerability must always be viewed as *an opportunity to empower health and healing through our shared humanity*. In order to do that, we must stop blurring the lines of our health system and just remove the lines.

No more "us and them." No more "carve outs."

Teresa & her son, Danny



No more cherry picking based on luck, heroics, zip code, or diagnosis. No more drivers of disparity and discrimination for sons like mine.

We must all work together in authentic partnerships where we can design a system that includes a continuum of psychiatric care from crisis, acute, subacute, and an array of supported housing that allows everyone to live and die with dignity.

This is Housing That Heals. I have seen it. I know it is possible.



Introduction

It is said that “home is where the heart is.” We agree, as two moms who have trauma tattoos on our hearts from years of watching our sons suffer because of a serious mental illness (SMI).

A health care system that includes a tiered array of *Housing That Heals* as part of a full continuum of psychiatric care will help mend our broken hearts and bend the harm curve for families like ours.

This document is not a white paper; it is a *heart paper* that weaves together the story of two families living the “California Dream” that turns into a nightmare of navigating California’s mental health care system. It is about two *Moms on a Mission* to find Housing That Heals for people who are living heroically with SMI. It is about two moms who have sat in local and state meetings for years, watching minutes endlessly taken while our life clocks tick away and our sons fall off the edge of cliff, after cliff, after cliff, taking us with them. We have witnessed countless housing plans envisioned, planned, and prioritized but never implemented, while our sons have been either homeless, incarcerated, or placed in multiple levels of poor quality hospital-based or community housing. Like so many other parents, we carry the fear about what will happen when we are gone and wonder if our sons will be left with “no place like home.”

In January 2019, we set out on a journey to see if we could find the best models of Housing That Heals in California. We set out in search of knowledge that might help answer some of the questions that we have heard endlessly debated while the fiscal and human waste grows. We set out looking for solutions that will cure a health system that is often too rigid, harmful, inhumane, and broken. We set out with a focused vision of hope that we would find existing Housing That Heals for the most severely mentally ill populations who rely on the California health care safety net. We wanted to know where the homes of hope are in California for those living with SMI. We wanted to explore whether a strategic expansion of Housing That Heals for the SMI population would help reduce suffering, save money and possibly our state’s soul.

We did find hope. We found people who care deeply, building what we dream of for our families. We found compassionate, kindhearted people who are committed to helping families like ours. We discovered that there are places of healing and humanity sprinkled across the state. We found that when California counties invest in building a psychiatric continuum of care, people who live heroically with SMI will come, and they will stay, and they will live in optimal health, stability, safety, and peace. And we found that if you move with deliberate determination to grow relationships, you will develop purposeful partnerships that will use common ground to build health, humanity, and Housing That Heals, together.

However, we also found that housing for those who have SMI is impacted at every level. This heart paper is not only about the current California *homeLESSness* crisis. It is also about building a system of *homeFULLness* along a quality continuum of psychiatric care. This paper will reflect the listening and learning tour we have taken through many California counties. It is our intention to personalize the policy, process, and political parts of health and care. We will include in this heart paper, data to inform and also *data of the soul* to identify solutions that can lead to systemic change. We will present our positions coming from the perspective of being mothers, community volunteer advocates, and activists focused on the SMI population that includes our beloved sons.



*Housing That Heals:
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We believe that when you start from a place of pain, feel it, and then share it, you will shatter the shame of the patients, the families, and the providers who serve them. You will come to understand that it is a universal pain for all who depend upon and work within the mental health care system.

Defining the Housing That Heals Problem in California

The Institute for Healthcare Improvement's (IHI) Triple Aim¹ framework suggests that if you improve both the patient experience and the population's health, you will reduce health care costs. This framework is considered a compass for optimizing a health system's performance. It has been used as a value-based goal in numerous health care system improvement efforts for the larger "mental health" or "behavioral health" populations. It has been said that the Triple Aim will not be achieved until there is a focus on the SMI population. This focus will reveal one of the greatest health disparities presenting in our California communities and public health and safety systems.

According to a 2006 report by the National Association of State Mental Health Program Directors, "people with SMI experience health disparities and die early. Many of the causes of premature morbidity and mortality are related to the vulnerability of the population with SMI."² The report suggests that providing "safe housing" for the SMI population is one factor that could help ease the burden of these illnesses.

What are the key drivers of the inequalities in health and care for this complex population that has led to what some refer to as a humanitarian crisis? This crisis has filled our jails, streets, hospital emergency rooms (ERs), elderly parents' back bedrooms, and graveyards with people who need(ed) help and care. We hypothesize that there are four key drivers of despair and disparity impacting the ability to develop a continuum of psychiatric care and Housing That Heals in California:

- Lack of a shared definition of SMI in the medical, social justice, courts, detention, and community health delivery systems.
- Legal fiscal discrimination codified in the California Welfare and Institution Code and Federal Medicaid Rules.
- Ideological tension – Medical Model vs. Recovery Model – prevents true system transformation for the SMI population.
- Lack of a tiered level of bed capacity and a fluid system in and out of levels of care.

¹ <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>

² Parks J, Svendsen D, Singer P, Foti ME, eds. Morbidity and mortality in people with serious mental illness. National Association of State Mental Health Program Directors. 2006.

https://www.nasmhpd.org/sites/default/files/Mortality%20and%20Morbidity%20Final%20Report%208.18.08_0.pdf



Drivers of Despair and Disparity for SMI in California

Does the Lack of a Shared Definition of SMI Create a Barrier to Housing That Heals?

The current lack of a universally accepted definition for SMI in California may be preventing progressive and coherent reform for this most vulnerable population. While we know that there is a spectrum of mental illnesses from mild to severe and often co-occurring developmental and substance use disorders (SUDs), California has intentionally segregated and conflated their delivery systems and funding streams, all in the name of Behavioral Health Integration and Whole Person Health Care Reform.

California's specialty mental health population is still carved out and separated.³ Despite years of tests, pilots, and promises of integration, this most vulnerable population is historically lost in the shuffle. Therefore, it might be said that one of the main drivers of despair and disparity for the SMI population is the lack of a universal definition of serious mental illness. Because different definitions produce different numbers, populations, and population characteristics, the lack of a common definition complicates analyzing and reporting the role and impact of SMI.⁴ It was noted as early as 1999 by the LPS Reform Task Force that the original Lanterman-Petris-Short (LPS) Act intentionally omitted a definition of mental illness based on the changing social views at the time and that the LPS Act's "lack of clear definition and common misinterpretation of its provisions have caused inconsistent application from county to county."⁵ The Task Force recommended that the LPS Act should be amended to include a clear definition of mental illness that represents the current scientific knowledge.

According to the *Californian Mental Health Master Plan: A Vision for California Report* delivered to the Legislature in 2003, "With the passage of the realignment legislation in 1991, the adult target population definition was put in statute. Welfare and Institutions Code Section 5600.3 describes the target population for adults with mental illness who are served by the public mental health system. That definition states that a client's mental illness must be severe in degree and persistent in duration; may cause behavioral functioning that interferes substantially with the primary activities of daily living; and may result in an inability to maintain stable adjustment and independent functioning without treatment, support, and rehabilitation for a long or indefinite period of time."⁶ The 2003 California Master Plan further described the managed care definitions of "medically necessary care" for recipients of specialty mental health services when the Short/Doyle Medi-Cal mental health services were combined with the fee-for-service Medi-Cal: "Eligible care for medically necessary services must be focused on the impairment, the client must be expected to benefit from the intervention, and the conditions should not be responsive to treatment that could be provided by the physical health care system."⁷

³ https://www.dhcs.ca.gov/services/Pages/Medi-cal_SMHS.aspx

⁴ <https://www.treatmentadvocacycenter.org/fixing-the-system/features-and-news/3771-research-weekly-what-is-qserious-mental-illness>

⁵ <https://mentalillnesspolicy.org/states/california/a-new-vision-for-mental-health-treatment-laws-a-report-by-the-lps-reform-task-force-pdf.html>

⁶ <https://www.dhcs.ca.gov/services/MH/Documents/CA%20Master%20Plan.pdf>, p.68

⁷ Ibid.



In 2004, the generous voters of California supported Proposition 63, a “millionaires’ tax” by initiative. When the implementation began in 2004-2005, Proposition 63 became the Mental Health Services Act (MHSA) and was promised to be the defining law for the Specialty Mental Health delivery system transformation and a dedicated funding source for the long-studied and proven model “system of care for children, adults and older adults who were defined by WIC 5600.3.” The original ballot language clearly defined how this Act would be applied to the carved out public specialty mental health population.⁸ However, the history of the MHSA’s implementation has been controversial and widely debated. It has been the source of multiple state and local audits, lawsuits, Little Hoover Commission reports, a variety of formal research studies, and independent investigative reporting.

As a result, the legislature and Governors have modified the purpose and intent of the original Act and re-defined the definition of the Welfare and Institutions Code (WIC) 5600.3 specialty mental health population numerous times since 2004. The latest amendment made to the WIC 5600.3 population definition was in January 2019.⁹

In 2012, the LPS Task Force II report issued several recommendations.¹⁰ The first recommendation was in regard to the definition of “grave disability” and suggested that a determination of grave disability should be altered based on a person’s capability to provide food, shelter, safety, and medical care for themselves. It also called for the grave disability standard to be redefined with specific criteria that considered both the historical course of the illness and the current capacity of the individual to make informed medical decisions along with the probability of significant harm without adequate treatment.

In August 2017, a criminal justice-focused workgroup in California agreed that a shared definition of *serious mental illness* was an important first step to create a universal language across counties. The group made a collaborative decision to interpret WIC 5600.3(b) into simpler common language and to promote its use as a *model shared definition*. However, this definition is offered as a guidance tool only and is not mandated.¹¹

Model Shared Definition

A common language interpretation of Welfare and Institutions Code (WIC) §5600.3(b)

Serious mental illness is a severe disabling condition which impairs behaviors, thoughts, and/or emotions. Without treatment, support, and rehabilitation, serious mental illness may interfere with the ability to do any or all of the following: manage activities of daily living, function independently, maintain personal or community safety, achieve emotional or cognitive stability, and/or develop and sustain positive relationships. Serious mental illness includes, but is not limited to, schizophrenia, bipolar disorder, post-traumatic stress disorder, as well as major affective disorders or other severely disabling mental disorders. Individuals with serious mental illness may also have substance use problems, developmental disabilities or other physical illnesses.¹¹

⁸ https://repository.uchastings.edu/cgi/viewcontent.cgi?article=2224&context=ca_ballot_props

⁹ http://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=WIC§ionNum=5600.3

¹⁰ http://www.vhca.org/images/BH/PDF/BHAB/Adults/LPS_Reform_Task_Force_Report_March_2012.pdf

¹¹ <https://stepuptogether.org/wp-content/uploads/2018/04/Model-Shared-Definition-of-SMI-Practical-Strategies-for-Its-Use-to-Reduce-the-Number-of-People-with-Mental-Illnesses-in-California%E2%80%99s-Jails.pdf>



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In this section, we have highlighted the history of the multiplicity of definitions that clearly contribute to the confusion of who will receive treatment and what that treatment will be. The State lumps any mental illness and substance use disorders under a “behavioral health” umbrella and calls them “mental health challenges” or “behavioral health problems.” These terms imply that they are just *bad behavioral choices* rather than symptoms of a brain illness that require medical care, adding to the public’s misperception. Further complicating the matter, California has 58 counties ranging in size from under 100,000 to over 12 million in population. Some counties contract out for all mental health services, some provide all services themselves, and others form a consortia to jointly provide or contract for the full array of services. Even the definition of SMI is left to individual counties to decide in negotiation with the managed care plans. Therefore, it is not surprising that there is a wide divergence of services.

In this paper we will use the current WIC 5600.3(b) definition¹² because this is in California statute and is the legal definition.

Does Fiscal Discrimination Drive Housing Disparity for the SMI Population of California?

In 2019, CalMatters.org wrote an exposé providing useful data that helps frame the “sweeping crisis” that is permeating our state.¹³ While the report states that “1 out of every 24 [Californians] have a mental illness so serious it becomes difficult for them to function in daily life,” it also notes the co-occurrence of substance use with mental illness. This highlights one of the State’s delivery system design and financing flaws since *SMI and SUDs are managed in two separate delivery systems with separate waivers and funding streams.*

The California behavioral health system continues to create separate and unequal access to medically necessary care and appropriate housing programs for both the SMI and SUD populations. There is no true integration, parity, or equity for the carved out specialty mental health population of California.

Not even the billions of dollars of MHSA funding have been able to systemically bend the harm curve for this population. The complexity of the California public mental health funding history is well documented. However, how that money is distributed among different mental health populations is not an easy path to follow.

Many advocates believe that it is hard to “cry poor” when so many California counties are sitting on millions of dollars in MHSA funds. And, while many politicians, policymakers, and stakeholders are focused on parity for the privately insured, many ignore the lack of access to a full continuum of care for the WIC 5600.3(b) specialty mental health population. This lack of focus is keeping too many people with serious and persistent mental illnesses housed in bedbug-infested single-room occupancies, solitary jail pods, cardboard tents, or in locked Institutions for Mental Diseases (IMDs) far away from family, friends, conservators, and case managers.

It is criminal negligence for counties to be sitting on funding while so many diagnosed with SMI are suffering without access to appropriate and medically necessary hospital-based or community-based treatment, quality housing and other social determinants of health.

¹² http://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?sectionNum=5600.3.&lawCode=WIC

¹³ <https://calmatters.org/articles/breakdown-californias-mental-health-system-explained>



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National conversations about the broken mental health system often refer to a lack of dedicated funding. When it comes to California, people from other states often wonder why things are in such crisis since we have dedicated Realignment funding,^{14,15} MHSAs billions and the large influx of funding from the Affordable Care Act (ACA) Medicaid Expansion.^{16,17} Few people understand the legal and fiscal discrimination against the 5600.3 specialty mental health population in California. When we divert funding to other social entitlement programs or to “any mental illness” that may or may not be “serious” and then cut the Realignment budget, we prevent counties from providing adequate and medically necessary treatment in a Mental Health Rehabilitation Center (MHRC) or IMD for people living with SMI.

Realignment or County General Funds are the sole source of funding for locked IMDs in California because the Federal Medicaid IMD Exclusion¹⁸ prevents states from using federal Medicaid funding for long-term psychiatric hospital beds in facilities with more than 16 beds. This is one of the main reasons that acute and sub-acute hospital beds have closed in California. There is often a direct correlation made between the closing of hospital beds and the increase in mental health jail cells occupied.¹⁹

Many do not realize that federal and state parity does not apply to those on Medicaid/Medi-Cal and Medicare. Mental health parity is a widely discussed topic among all mental health and behavioral health stakeholders. Most health advocates agree that there must be equity in access to mental health care equal to physical health care. National and state mental health organizations call for parity accountability under the ACA and the new Mega Rule.²⁰ However, there is a lack of discussion about the codified fiscal discrimination that exists in the WIC for the carved out 5600.3 SMI population. We do not manage care “only to the extent resources are available”²¹ for any other illness in California. Efforts to correct this inequity go back to the heroic work of California Representative Helen Thomson in 1999 when she succeeded in passing the California parity law, AB 88, for the commercially insured population. Unfortunately, Thomson's effort to strike the fiscal discrimination language from WIC 5600.3 was rejected by the legislature in 2002; thus, leaving the public Specialty Mental Health Services (SMHS) unequally funded and its beneficiaries unequally treated.²²

The ACA added “essential benefits” for “mental health” care if you have a mild or moderate mental illness. However, they do not apply to specialty mental health clients. Therefore, county conservators are unable to access step down programs for their clients in locked settings, so the clients end up in higher, more expensive levels of care for longer than medically necessary.

¹⁴ https://www.cibhs.org/sites/main/files/file-attachments/1_25_2019_sc_issues.pdf?1549648341

¹⁵ <https://www.chcf.org/wp-content/uploads/2017/12/PDF-ComplexCaseMentalHealth.pdf>

¹⁶ Ibid.

¹⁷ <https://www.ppic.org/publication/the-affordable-care-act-in-california>

¹⁸ <https://www.treatmentadvocacycenter.org/storage/documents/backgrounders/imd-exclusion-and-discrimination.pdf>

¹⁹ https://www.treatmentadvocacycenter.org/storage/documents/final_jails_v_hospitals_study.pdf

²⁰ <https://www.dhcs.ca.gov/formsandpubs/Pages/FinalRule.aspx>

²¹ <https://lhc.ca.gov/sites/lhc.ca.gov/files/Reports/157/Report157.PDF>

²² http://file.lacounty.gov/SDSInter/dmh/224072_LittleHooverReportonProp63.pdf



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This is an Olmstead violation that no one seems to address.²³ The SMI population served in California's public mental health system is denied parity – the right to treatment for the carved out specialty mental health population is waived.

While California's current 1115 Waiver allows SUD patients to receive Medi-Cal-covered care in an IMD, there is no current equivalent waiver for the specialty mental health population. The Center for Medicare & Medicaid Services (CMS) has issued guidance that would allow California to amend their 1115 Waiver and receive reimbursement for up to 30 days of medically necessary treatment for SMI in an IMD. However, the California Department of Health Care Services (DHCS) leaders continue to question the feasibility of the waiver.²⁴ This *must be a priority* for California's DHCS and legislature in the upcoming waiver process. The IMD exclusion is the key driver of discrimination from the Federal Government.

California furthers this financial discrimination by funding community services “only to extent resources are available” and then spending those resources on the populations and social programs who have a right to treatment under the ACA and other regulatory avenues, such as Autism, Intellectual and Developmental Disabilities (IDD), Mild/Moderate Mental Illnesses, Foster Care.^{25,26}

The lack of understanding about the different funding entitlements available to different populations also leads to extreme confusion. The California Lanterman Act²⁷ was a hard fought win for the IDD community that established critical resources that would allow this population to live in the community versus institutional settings and receive supports commensurate with level of ability. These entitlements can range from \$1,058 to \$8,319 a month.²⁸ This population has a right to shelter, a right to treatment, and a right to in-home supportive services which provide an improved quality of life opportunity in the least restricted environment. However, there is no equal entitlement for the SMI population. This pits two vulnerable, disabled communities against each other in a fight for resources.

Does Ideology Drive Disparity for the SMI Population – Medical Model vs. Recovery Model?

There are many people in the SMI population who are so ill that they do not respond to treatment in a voluntary community setting. The “no wrong door” mantra of recent years is laudable. However, there are people who are not capable of answering the door when their family, Full Service Partnership (FSP) clinician, or peer is knocking.

Treatment needs for some people living with SMI are more complicated than what was envisioned when the state hospitals were emptied with the assumption that community treatment would replace the need for large institutional settings. There is now the recognition that, due to the severity of one's mental illness, some will experience acute episodes that require inpatient treatment. There is also the reality that not all people living with SMI can achieve recovery to the point where they can live on their own without an intensive support system.

²³ <https://supreme.justia.com/cases/federal/us/527/581>

²⁴ <https://www.dhcs.ca.gov/provgovpart/Documents/CalAIM/BH-Workgroup-SMI-SED-IMD-Discussion-11-08-19.pdf>

²⁵ <https://www.auditor.ca.gov/reports/2017-117/sections.html>

²⁶ <https://mentalillnesspolicy.org/wp-content/uploads/statewide-mhsa-missspending.pdf>

²⁷ <https://www.dds.ca.gov/transparency/laws-regulations/lanterman-act-and-related-laws>

²⁸ https://www.dds.ca.gov/wp-content/uploads/2019/12/CCF_Rates_January2020.pdf



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There needs to be a continuum of care available to everyone, not just for those who are well enough to open the door.

- The **Recovery Model** is a holistic, person-centered approach to mental health care. This has allowed it to gain momentum and is becoming the standard model of mental health care. This model is based on two simple principles: 1) It is possible to recover from a mental health condition; and 2) The most effective recovery is patient-directed. The fact that many people do not fully recover from a mental illness or that they experience life altering relapses brings in the necessity of the Medical Model.
- The **Medical Model** holds that mental illness is a psychiatric disease with a physical explanation that can be addressed with medical treatment. It has proven highly successful and even indispensable in many contexts; it is difficult to name a plausible alternative to medical diagnosis and treatment for a person who is a danger to themselves or others. The medical model embodies basic assumptions about medicine that drives research.

There is much strife within the community dedicated to helping those with a mental illness. The Recovery Model holds that no one gets better unless it is voluntary. The Medical Model holds to the principle that medical intervention, conservatorship, and assisted outpatient treatment are often necessary when a person lacks insight into their condition. There does not have to be an either/or system. There can be a system of care that is both/and. For some the Recovery Model is successful; yet, for others it has been disastrous. These outcomes create the need to marry the Medical Model and the Recovery Model and weave the medical and clinical supports into the daily living environment to support recovery.

Does the Lack of Tiered Levels of Care Capacity Create Human and Fiscal Waste?

There is no lack of information about the current humanitarian crisis due to an inadequate supply of psychiatric beds in California for the SMI population. And it is no longer a secret that county jails are the largest providers of mental health services.²⁹ Extraordinary investigative reporting has brought awareness to the clogs and bottlenecks occurring due to the lack of a continuum of care. This paper will refer to this phenomenon as “*the human log jam*” because it is human beings that are being impacted, not widgets in a machine or parts on an assembly line.

“Our jails have become the beds that never say NO.”

Mark Gale, NAMI Los Angeles County Council, Criminal Justice Chair

There is a human and fiscal shell game taking place and a bed dance that shuffles individuals with SMI from ERs and crisis stabilization units to the streets and to solitary confinement and back around again. The inhumane revolving-door crisis – sometimes grossly called “catch and release” – is now widely known.

And, because families are no longer staying silent, it is no surprise that they often go to heroic measures to house and care for their seriously mentally ill family members, sometimes risking their own health and security.

²⁹ Susannah Cahalan. *The Great Pretender: The Undercover Mission That Changed Our Understanding* (Grand Central Publishing, 2019).



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A recent Facebook blog diary called “Broken” has been capturing this chilling California care crisis in real time over the past several months.³⁰ It is a typical and classic story of a parent who will go to any length to provide care and safety for her family member living with SMI. This story should be required reading for any administrator or policymaker that is leading a whole health system reform.

Some say that the first thing that must be done to solve a problem is to reach an agreement on what the problem is that needs to be solved. While there is no longer a debate about the current humanitarian crisis in California, there is still great social, political, financial, and ideological conflict about how it must be resolved. There is still tension over who deserves a bed instead of a tent, a jail pod, or mom’s back bedroom. Some people believe that a right to shelter and housing must come first with promises of support and treatment to follow. This was the argument made to the voters in 2018 when they supported Proposition 2’s No Place Like Home (NPLH) bond plan.³¹ Many SMI advocates opposed this housing bond plan because it would drain one of the only sources of funding for community-based treatment and put more SMI people at risk of homelessness. While the unsheltered homeless crisis has reached a tipping point and is rightfully being addressed, there is not enough attention on the SMI subpopulations most at risk of or intermittently experiencing homelessness, including those who are:

- living with aging parents.³²
- discharged from Emergency/Crisis Stabilization Units/Psychiatric Emergency Services.
- living in inappropriate community levels of care without adequate support.
- at risk of eviction from an Adult Residential Facility.³³
- displaced by natural disasters.³⁴
- displaced by business failures.³⁵
- transitioning from state hospitals, locked acute or IMD settings to community placement due to inadequate support.
- transitioning from incarceration.³⁶

Recent reporting focusing on San Francisco highlights the decision-making mystery surrounding placement decisions and filling beds. “At least 18 ARF patients and their families were blindsided by a recent 60-day relocation notice. Outrage over the move grew after it was revealed that 32 of the 55 ARF beds have gone unfilled for nearly a year, despite an urgent need for assisted living placements. Department of Public Health leaders have cited staffing issues as a reason for the empty beds and said the ARF beds were underutilized.”³⁷

³⁰ <https://www.facebook.com/OurBrokenSystem>

³¹ [https://ballotpedia.org/California_Proposition_2,_Use_Millionaire%27s_Tax_Revenue_for_Homelessness_Prevention_Housing_Bonds_Measure_\(2018\)](https://ballotpedia.org/California_Proposition_2,_Use_Millionaire%27s_Tax_Revenue_for_Homelessness_Prevention_Housing_Bonds_Measure_(2018))

³² <https://www.socialworktoday.com/archive/111511p18.shtml>

³³ <https://sfist.com/2019/08/26/breeds-bed-cuts-to-residential-mental-health-programs-draw-outrage>

³⁴ <https://keyt.com/news/2018/05/10/crews-working-to-restore-burned-down-ventura-mental-care-hospital-as-soon-as-possible>

³⁵ <https://www.sfchronicle.com/business/article/Anka-Behavioral-Health-files-for-bankruptcy-13811596.php>

³⁶ <https://www.nami.org/Find-Support/Living-with-a-Mental-Health-Condition/Reentry-After-a-Period-of-Incarceration>

³⁷ <https://www.sfexaminer.com/news/supervisor-presses-for-quick-reopening-of-long-term-mental-health-beds>



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While there is extensive new reporting on the issue, there are also reams of historical process and papering that demonstrate that this has been an ongoing policy debate in California since the deinstitutionalization from state hospitals. Sadly, instead of following the well-studied, evidence-based recommendations provided in the California Master Plan of 2003³⁸ when Proposition 63 was passed in 2004, endless new *stakeholder theater* sessions were commenced to develop *new* recommendations and plans, seemingly intent on “reinventing the wheel.”

The recent work of the California Behavioral Health Planning Council (CBHCP) have added in-depth knowledge to the recent reporting burst on this issue. The 2018 report on ARFs coupled with the great work in Los Angeles and San Francisco Counties,³⁹ have enlightened policymakers and the public and brought much needed attention to the gaps in access to housing options for individuals living with SMI. These papers, along with the attention from The Steinberg Institute at their April 2019 forum,⁴⁰ has created a surge in clear calls for plans of action, not just more planning.

While there is a new and welcomed wave of information on the SMI housing crisis, there is still a serious gap of understanding and transparency about how placement decisions are made and prioritized. The following questions must be answered:

- Who holds the key to unlock the door to free the SMI human log jam in California? Is it the DHCS, Dr. Tom Insel (California’s current Mental Health Czar),⁴¹ the Legislature, or the Governor?
- Where is the oversight? Is it the Mental Health Services Oversight and Accountability Commission or the local Mental Health Boards? Or, is it left up to reporters, families, and moms to blow the whistle?
- Who are the gatekeepers of acute psychiatric beds, IMD beds, MHRCs, and Board and Care/ARF beds in each county?⁴²
- How do Specialty Mental Health Plan Administrators and Public LPS Conservators make placement decisions?
- What is the court’s role in determining who gets a bed instead of jail cell?
- How do families know if all levels of treatment beds are being fully utilized?
- How can the public trust “the system” to create solutions when there is endless reporting of entire units being unused and front page wars between city mayors, Board of Supervisors, line staff, labor unions, hospitals, and health plan leadership?⁴³

***California has had many mental health “blueprints” and “roadmaps” over the years.
What may be needed now is a moral compass.***

³⁸ <https://www.dhcs.ca.gov/services/MH/Documents/CA%20Master%20Plan.pdf>

³⁹ <https://www.dhcs.ca.gov/services/MH/Documents/Legislation-Committee/2018-ARF-Final.pdf>

⁴⁰ https://www.dhcs.ca.gov/services/MH/Documents/Legislation-Committee/April_2019_Leg_Packet.pdf

⁴¹ <https://californiahealthline.org/news/governors-mental-health-czar-seeks-new-blueprint-for-care-in-california>

⁴² <https://www.sfchronicle.com/politics/article/Mayor-pulls-out-of-talks-on-San-Francisco-mental-14468605.php?psid=jPeXz>

⁴³ <https://www.sfchronicle.com/politics/article/Mentally-ill-man-moved-from-jail-to-treatment-so-14471643.php>



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Evidence: Data + Data of the Soul

There is plenty of evidence to demonstrate *the human log jam* across California counties due to the lack of a housing continuum of care for the most seriously mentally ill population. A visit to any medical emergency room, psychiatric emergency room, psychiatric inpatient unit, homeless shelter, IMD, county jail, or courtroom will reveal the humanitarian and moral crisis. A historical review of California's mental health care reform efforts going back to the eighties and nineties reveals mountains of mission statements, visions, strategic models, and Master Plans.

Years of learning led to the bold effort to pass Proposition 63 in 2004. The California Master Plan of 2003 was issued to the legislature and might be considered as a baseline report to measure California's specialty mental health system of care progress in 2019. The 2003 Master Plan included years of prior studying, data collection, meetings, and mappings. It has been followed by *years* of high-cost consulting, "stakeholder theater," and plans created. And, those plans have led to multiple "pilot projects to nowhere" while people who live with SMI are slowly dying.

We include what we call "data of the soul" throughout this document, which is our lived experience with care and housing to augment the evidence base for our Moms on a Mission journey. The recent investigative reporting cited in every major newspaper in California hits the hot spots facing California's mental health systems of care and provides clear evidence and context to consider whether a lack of a full continuum of psychiatric services that includes quality Housing That Heals for the SMI 5600.3(b) population is contributing to a humanitarian crisis. However, we offer the view through the prism of a mom's tears and hopes.



The Journey Begins

As Moms on a Mission, we drove over 3,170 miles during 2019 on a journey to look at the housing options available to those living with SMI because, for decades, many families like ours have been trying to get housing built that meets the needs of their family members who are unable to live with them. These family members were residing on the streets, in jails, or leading a grim existence in care homes with insufficient or untrained staff because all potential placements were full. Our goal was to discover, and then highlight for county, state, and federal administrators, what is working and what is not working in the current continuum of care in California for those living with SMI.

For this project we have concentrated on twenty-two facilities that range from a Mental Health Rehabilitation Center to a Peer Respite Center. The criteria we used to evaluate the housing options we visited was the Institute of Medicine's six specific aims⁴⁴ that a health care system must fulfill to deliver quality care, including:

- **Safe:** Care should be as safe for patients in health care facilities as in their homes.
- **Effective:** The science and evidence behind health care should be applied and serve as the standard in the delivery of care.
- **Efficient:** Care and service should be cost-effective, and waste should be removed from the system.
- **Timely:** Patients should experience no waits or delays in receiving care and service.
- **Patient-centered:** The system of care should revolve around the patient, respect patient preferences, and put the patient in control based on ability and capacity.
- **Equitable:** Unequal treatment should be a fact of the past; disparities in care should be eradicated.

At the start of our journey we had hopes of finding at least one facility that could be a blueprint for others to follow; it turned out that we found many good facilities that were effective in providing care and treatment.

However, most would not accept individuals who had a difficult history. This causes the phenomenon that we moms call "cherry-picking," leaving the hardest-to-treat people relegated to the streets and shelters.

We found two things that all the facilities we visited had in common:

- They are safer than the streets.
- They were not always available to those who needed them.

⁴⁴ Institute of Medicine. 2001. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: The National Academies Press. <https://doi.org/10.17226/10027>.



Facilities Visited January – December 2019

Facility Name	Organization	County	Program Type
Moore Village	John Henry Foundation	Orange County	Community-based residential treatment on-site mental health services/licensed ARF
Kirker Court Apartments	Eden Housing	Contra Costa County	Affordable housing designated for SMI
Garden Park Apartments	Hope Solutions	Contra Costa County	Affordable housing/family-only On-site mental health services
AOT Pittsburg	Mental Health Systems	Contra Costa County	Master leased shared housing
AOT Antioch	Mental Health Systems	Contra Costa County	Master leased shared housing
The Family Courtyard	United Family Care, LLC	Contra Costa County	Residential care facility for the elderly with a mental illness/licensed RCFE
Brookside Shelter	Shelter, Inc.	Contra Costa County	Adult emergency shelter
Anne Sippi Ranch	Riverside Ranch, ASC Treatment Group	Kern County	Community-based residential treatment facility with direct access to a specialty mental health outpatient clinic/licensed ARF
Enclave at the Foothills	Ever Well Integrated Health Care	Kern County	Community-based residential treatment facility (currently under construction)
Foothills at the Alta	Psych/Social Rehabilitative Services	Tulare County	Residential care for elderly with psych/social rehabilitative services/licensed RCFE
Enclave at the Delta	Ever Well Integrated Health Care	San Joaquin County	Community-based residential treatment facility with psych/social rehabilitative services/licensed ARF
Delta at the Sherwoods	Ever Well Integrated Health Care	San Joaquin County	Community-based residential treatment facility for seniors providing psych/social rehabilitative services/licensed ARF
Delta at the Portside	Ever Well Integrated Health Care	San Joaquin County	Residential care facility for the elderly with psych/social rehabilitative services (currently under construction)
California Psychiatric Transitions	California Psychiatric Transitions	Merced County	Mental health rehabilitation center
The Farmhouse	Yolo Community Care Continuum	Yolo County	Adult residential treatment facility
Crestwood Healing Center	Crestwood Behavioral Health, Inc.	Contra Costa County	Community-based residential treatment facility providing psych/social rehabilitative services/licensed ARF
Nueva Vista Morgan Hill	Psynergy Programs, Inc.	Santa Clara County	Community-based residential treatment facility with direct access to a specialty mental health outpatient clinic/licensed ARF
Nueva Vista Sacramento	Psynergy Programs, Inc.	Sacramento County	Community-based residential treatment facility with direct access to a specialty mental health outpatient clinic/licensed ARF
Second Story	Encompass Community Services	Santa Cruz County	Peer respite center
Oxford House	Oxford House, Inc.	Contra Costa County	Self-run, self-supported addiction recovery homes



The John Henry Foundation (JHF) – Moore Village

Moms on a Mission began with a trip to Santa Ana in Orange County to visit with Mary Ellen Stuart, a member of the JHF Board of Directors. When one passes through the gates of JHF, one enters a therapeutic enclave created for approximately 37-42 people living with schizophrenia spectrum disorders. There are beautiful grounds surrounded by yellow and white cottages. The cottages each house 4-6 residents who have their own or shared rooms. The residents in each cottage share a bathroom and common room with a couch and TV. Various community buildings surround the beautifully-kept grounds.



As Mary Ellen shared with us: “My brother was never hospitalized during his nine years living at John Henry. That was a blessing with untold value, both in terms of money and emotional toll.” Mary Ellen also shared the loving care that was provided to her brother when he was diagnosed with a terminal illness. He received ongoing support from the JHF peer and clinical community while receiving hospital care. In order for him to return to JHF during recovery from treatment, JHF staff trained to care for his feeding needs which eventually included feeding tubes.

The JHF community is designed to accommodate individual differences through structured clinical, recreational, educational, employment, and volunteer opportunities. They have found that family interaction is a vital component in the treatment of its residents. Life at JHF revolves around the community model with a structured program that instills freedom of choice coupled with consistency of quality clinical care. Daily morning meetings where all of the residents meet in the community room brings everyone together and facilitates a daily check-in. Following the morning meeting, there are regular outings and opportunities for work and school. There are other weekly event requirements that the residents can select to attend, such as group sessions and outings.

Dr. Andrew Kami, the Clinical Director, specifically discussed the need to limit meetings for people on the schizophrenia spectrum based on their brain illness. This is in contrast to many IMD/MHRC programs where there are mandated meetings, sometimes eight or more a day, which many people with SMI are incapable of managing.



Another unique strength is the opportunity to participate in computer games specifically designed to improve cognitive skills. This may account for the remarkable fact there has been only a handful of 5150s during Dr. Kami's seven years with the program.

JHF has been able to bring in UC Irvine Psychiatric Interns who receive training and real-world experience with SMI. JHF also has Psychology Interns through local colleges, so it is truly a winning combination for the residents and for the people who are committing their careers to serve this population. This is an excellent model for workforce development which could be a partial solution to the California crisis of care providers. Facilities such as JHF are a gift to their residents and, in turn, to the families of their residents.

While it costs \$42,000/year to let someone live at the John Henry Foundation, it is estimated to cost \$40,000/year to let someone live on the streets and \$81,000/year to let someone live in a jail cell.

Kirker Court Apartments

The semi-rural area of Concord on Kirker Pass Road is the site of ten one-bedroom apartments and ten two-bedroom apartments where many people living with SMI reside. This community was developed by one of the largest nonprofit housing developers in the Bay Area in 1994, Eden Housing. The mission of Eden Housing is to build and maintain high quality, well-managed, service-enhanced, affordable housing that meets the needs of low-income families, seniors, and persons with disabilities. Eden Housing was sought out in the early 1990's by dedicated and committed families who were very concerned where their loved ones would live when living with their parents was no longer a workable option because of their parents' age or their child's mental illness. These families arranged to have Clayton Valley Presbyterian Church donate the land where these beautiful units were built.

This area is pristine. The gardens surrounding each group of apartments is lush and creates a park-like setting. It seems as if one were out in the country; however, a large grocery store and many shops are located in a complex less than a quarter mile away. Residents interviewed on-site said they had waited for ten years for an apartment.





Garden Park Apartments

Located in Pleasant Hill, Garden Park Apartments is an outstanding example of what a provider such as Hope Solutions can do with a private/public partnership. At one time, this building was a dilapidated apartment complex; now it is an amazing space. The complex has twenty-two one-bedroom and six two-bedroom apartments, a swimming pool, play areas, and a garden. Each apartment comes furnished so that families can move into a truly functional home.



MHSA funds were used to build a Community Center that now houses offices for a Psychologist and Master Level Clinicians. Through the use of this Community Center, Garden Park residents have access to many needed supported services that assist them with their individual needs, including:

- Full-time licensed mental health providers for case management, crisis intervention, family counseling and support, and assistance with completing individualized family self-reliance plans.
- Four days per week homework club and pre-school programs focused on measurable academic outcomes, emotional health, and social development for youth.
- Summer youth enrichment programs.
- Educational programs that support employment, healthy lifestyles, and successful parenting and family life.
- Activities and social events aimed at creating a healthy and vibrant community.

Mental Health Systems' AOT Housing – Antioch & Pittsburg

Mental Health Systems is the Assisted Outpatient Treatment (AOT) provider of transitional housing in Contra Costa County. Mental Health Systems provides shelter through their own master leasing program for clients who request assistance. They have three master leased properties: one large new home in Antioch, a smaller home in Pittsburg, and a duplex in Richmond. In most cases, clients have at least one or more roommates. The homes are kept in good condition with housekeeping services and have well-stocked refrigerators and pantries.



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The home in Antioch has a beautiful backyard, patio, and pool table. Staff visit the homes for meetings and to check on the residents' well-being. Support services are on call 24/7 but are not located on-site (one staff member does reside at the Antioch home).



Mental Health Systems' Vice President, Rich Penksa, has an extensive background in housing for the most vulnerable. He manages over 700 units of permanent supportive housing and transitional supportive housing across the state. His understanding of the Homeless Emergency Assistance and Rapid Transition to Housing (HEARTH) Act, HUD programs on housing, and Public Housing Authorities has given him the ability to augment housing funding streams.



When asked his opinion on how housing resources could be increased, Mr. Penksa gave the following observation:

“Mental Health Systems uses MHSA funding for an array of housing for our clients. Those funds are best spent on short term stays and master leasing, while a client prepares for a permanent supportive housing (PSH) subsidy. A mature program utilizes subsidy carve outs received through either a carve out for special populations from the local public housing authority (PHA) or as a direct recipient of Continuum of Care – “New Projects.” The Contra Costa FSP and ACTiOn team have no PSH subsidy commitments at this time. The effect of not having PSH subsidies means the program will sustain a stagnant housed census with little movement and limited ability to serve more clients with housing. PSH carve outs shifts the funding burden to the PHA, allowing program MHSA Housing dollars to be freed up to spend on more clients.”

The critical problem of where clients will live upon graduating from AOT still remains; all permanent supported housing opportunities are full, especially for those living with SMI that also have disqualifying histories that prevent access to any housing units that do become available.

Family Courtyard

Part of the *Moms on a Mission* journey focused on Contra Costa’s West County. One of the largest Board & Care facilities, the Family Courtyard, is located here. Seventy people reside here, mostly adults age 60 and older who are diagnosed with a serious mental illness and who are uninsured or receive Medi-Cal or Medicare benefits.

The Family Courtyard assists clients with personal hygiene, daily living skills, prescribed medication, and transportation to medical appointments. When the MHSA Program and Fiscal Review of the Family Courtyard showed a lack of supportive services available to enrich daily life, the County began and staffed on-site enrichment programs for the residents.





Calli House & Brookside Shelter

The Moms on a Mission West County tour also included the property shared by Calli House and the Brookside Shelter. On a continuum of care, temporary supported housing is essential. Since this location is so close to the Family Courtyard, it was important to check in on this multi-purpose site. The information below is provided on the County website:⁴⁵

“At Calli House, there are daytime Drop-In services for runaway or homeless youth age 18-24 years and overnight Emergency Shelter for runaway or homeless youth age 18-24 years. All youth entering the shelter are provided a comprehensive assessment that identifies their needs and form the basis of their housing plan. Transitional age youth who cannot return home or are not ready to live independently may have the option to live at Appian House or Pomona St. Apartments.”



Prior arrangements had not been made to tour the inside of Brookside Shelter, so our tour was of the surrounding grounds. This area of Contra Costa County experiences a high rate of homelessness. The shelter accommodates approximately 80 men and women, providing them with the opportunity to connect with many essential life sustaining services such as meals, showers, laundry, phone, mail, and also, just as importantly, to connect with case management which includes mental health services and housing placement.

⁴⁵ <https://cchealth.org/h3/calli-house.php>



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There are many shuttered buildings on the Brookside Shelter site. There is a kitchen being operated by county programs out of the back of a large facility adjacent to the shelter. The front half of this building is no longer in use. The grounds of this property were clean and the parking area was maintained.

At the time of the visit, some people who were homeless had set up camp at the abandoned buildings on-site. There is also a tent encampment on the other side of the fence. It was most disturbing to find young children's homework assignments and drawings littering the area of the encampment.





The Farmhouse

The Farmhouse in Yolo County is a rural residential program founded by the Yolo Community Care Continuum in 1979 by a group of parents who wanted a home-like environment for their adult children who were diagnosed with mental illness. They envisioned a place where their children could receive professional and compassionate treatment in the community in which they grew up in. Though it began as a farm program, the Farmhouse has evolved into a rehabilitative transitional treatment environment where adults can learn the skills necessary to make a successful transition from a highly-structured treatment environment to a less restricted form of independent living. The prevocational program improves skills by providing the opportunity for residents to care for farm animals, tend the garden and assist in running the farm.

Lauren at The Farmhouse





Anne Sippi Ranch

Families in Contra Costa County tried for years, without success, to create a residential rural farm program with not only supportive services but also opportunities to explore expressive craft and artistic activities. It was envisioned that the residents would have equine therapy and the opportunity to work with the Master Gardening Program of the UC Extension Service. In the early 2000's, NAMI Contra Costa members visited Anne Sippi outside Bakersfield to see another rural property that was attempting a rural farm program. We wanted to touch base again with Anne Sippi to see how the project had evolved.

Things have changed. Anne Sippi's main house, which was part of the original Merle Haggard Estate, was still in use, complete with the guitar-shaped pool. Now, most of the residents have a dual diagnosis of mental illness along with a developmental disability. Residents under the care of the Regional Center with the dual diagnosis of mental illness and developmental disability are allotted a much higher amount of funding for their care than those who have a single diagnosis of serious mental illness.

There are no longer farming activities available. Instead, Anne Sippi has just opened a beautiful new treatment facility, beautifully appointed, dedicated to residents from Ventura County who have a serious mental illness. It is dedicated to serve residents that "nobody else would take." Anne Sippi has a Specialty Mental Health Clinic on-site so that billable, intensive therapy can be available to its residents. Anne Sippi also has plans to restore and renovate the guest house on the property into a housing opportunity where residents would have their own apartments. Anne Sippi provides its residents with much needed safety and security in a rural setting where they may live for months or years, depending on their need.



Having programs that give people second, third, and fourth chances is so needed for those living with a serious mental illness.

It touched both of our hearts since we both have sons that have burned many bridges.



Ever Well Integrated Health

Ever Well Integrated Health now has many facilities in different stages of development in the Central Valley of California. Founders Chris Zubiante and Andy Fetyko have a vision to provide compassionate treatment and care for those that no one else will take, and to build a system of abundance, not scarcity.



Their largest project is an immense undertaking; they are converting the old Lutheran Orphanage in Terra Bella. This project is located in a breathtaking rural setting at the base of the Sierras. A wing of this property has been fully renovated and will accommodate 40 people. There is amazing capacity and potential at this site. Ever Well has renovated a senior living facility in Dinuba with the latest design elements that will help residents feel more at home and less in an institution.

Ever Well Integrated Health has three facilities in Stockton. The first facility (pictured above) is in the countryside north of Stockton. Almost all residents living here have previously been at locked facilities. Many residents have a dual diagnosis of addiction and mental illness in addition to primary health problems that have prevented other providers from caring for them. This is a niche that Ever Well is filling; they are providing care for people no one else is willing to take, helping them to leave locked facilities and enter community settings.

Ever Well has a second facility in the heart of Stockton. It is a Residential Care Facility that provides mental health care and treatment to older adults. This facility is still in the process of renovation but has begun operation. The residents in this program have multiple medical issues along with a serious mental illness. This is not a locked facility, but most residents stay on-site. During the day, the schedule offers many activities. Art produced by those who live there enlivens every room on the premises.

A third Ever Well facility is located in the Port area of Stockton and had just been acquired. It is located in an older neighborhood adjacent to a large beautiful city park and recreation area. The staff training at Ever Well is rigorous. Food and its preparation are also seen as essential ingredients in attaining wellness.

***As we left Stockton that evening, we got lost and ended up in a homeless encampment area.
The significance of this was not lost upon us.***



California Psychiatric Transitions

California Psychiatric Transitions (CPT) is located in Merced County. Many California counties send their clients here who have struggled in lower levels of care. CPT is a 98-bed fully-licensed Mental Health Rehabilitation Center (MHRC) consisting of three facilities completely staffed with qualified, compassionate, and competent personnel. The Diversion Program is designed to serve court-ordered diversion and Incompetent to Stand Trial-Penal Code 1370 (IST 1370) individuals.



The Main Unit is focused on developing social skills, daily living skills, and in-depth awareness of behavior management and tools to support self-reliance. The focus of the Re-Entry Program is learning skills associated with independent living and vocational rehabilitation. The Disruptive Behavioral Unit program provides individuals with an intensive therapeutic program that focuses directly on minimizing disruptive behaviors in a highly-structured setting.

The program is highly structured in a tiered-level system and is an alternative to hospitalization at a state hospital. Clients must attend groups based on their individual treatment plan goals. The highest level of clinical and staffing support is provided. Off-site recreation and social activities are offered as appropriate. The program is very client and family centered. It provides a perfect blend of treatment and rehabilitative supports needed to stabilize symptoms, manage life skills, and restore health.





Teresa's son, Danny, was sent to CPT in 2016 on a 1370 IST in a unique arrangement between Contra Costa County and the Napa Superior Court. Because Contra Costa had maintained Danny's LPS Conservatorship during a four-year effort to establish competency, the Napa Superior Court, in partnership with the DA, Public Defender and CCC, agreed to send Danny to CPT instead of back to a state hospital. This freed up a state hospital bed and allowed Danny to go to a smaller, more therapeutic environment with a bed instead of a solitary cell. All criminal charges were eventually dismissed and the LPS Conservatorship was maintained. Danny was still in an involuntary program but free to heal and stabilize. He needed to be in a locked facility for a period of time in order to learn life skills that allowed him to successfully transition to a community placement at Psynergy in 2018. CPT was the "least restrictive" care that allowed Danny to free himself from the symptoms and the broken California system of care.

For 20 years, Danny and his family endured several acute hospital stays, PHFs, two state hospitals, many IMDs, MHRCs, and both small and Super Board & Care facilities. However, none were as successful as CPT. There should be a facility like CPT in every county. However, we need to stop federal, state, and local funding discrimination to make that happen. Some people think that people like Danny need to live in a state hospital for life. Not true. But people like Danny cannot live alone either without the right support and Housing That Heals. In Danny's case, CPT was the right level of Housing That Heals that allowed for his successful transition to a community placement.

Family Photo During a Visit with Danny at CPT





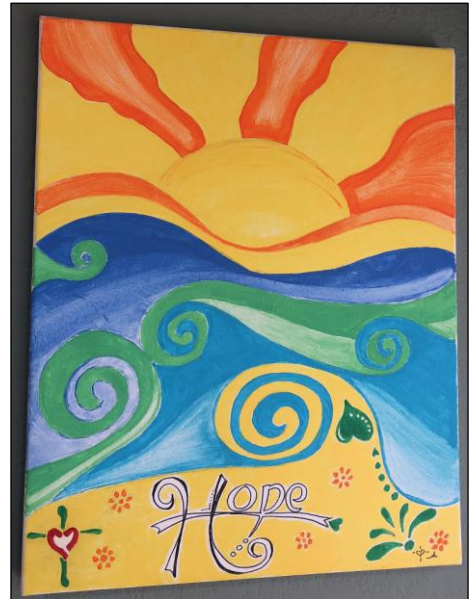
Crestwood Pleasant Hill

Crestwood Pleasant Hill is a facility that family members fought hard to open in 2003. The NIMBYism was horrible, but the fears have been proven unfounded. This treatment facility has not deterred families from making this area of Pleasant Hill, known as Poets' Corner, one of the most sought-after neighborhoods in Contra Costa County.

As Mental Health Commissioners, we both toured this facility between 2006 and 2015. Since then there have been needed upgrades made. Travis Curran is the Director and his office is filled with residents' artwork and photos, a testament to his commitment to his work.

Today, sixty-four people reside in this augmented "Super" Board and Care facility. The mission at Crestwood Healing Center is to enhance quality of life, social interaction, and community involvement for its residents so that they may attain a fulfilling life.

In addition, this facility has a sixteen-person program that provides clinical mental health specialty services for up to a year for those residents considered the most compromised by mental health issues. This program provides intensive training to promote independent living. Its objective is to ready residents for their own residence.





Second Story Peer Respite Center

Second Story is a six-bed home which serves as a respite and a voluntary opportunity for individuals to learn how to use their relationships and skills to establish a solid foundation that will enable them to return to their life in the community. This home is staffed by peers (people with lived experience).

Here, one has the opportunity to connect with others who are experiencing many of the same challenges they are. Dedicated trained peers guide those who are seeking respite. The hope is to generate some moments of connection and trust. It is hoped that lessons learned in this community experience will spill over into the future.



Along with creating a temporary home, this peer respite program exists to build a path towards wellness. It is not a substitute for psychiatric hospitalization. Those who are drawn to the program develop with staff a plan for dealing with feelings and behaviors that, in the past, have led to inpatient stays.

Second Story offers a stay of 13 days in a home environment and provides guests with opportunities to identify and plan for changes they feel will benefit them once they have returned home. All former guests are offered ongoing telephone support and are welcome to visit when they need encouragement from their peers and peer staff.

Second Story is part of Encompass Community Services, a nonprofit organization in Santa Cruz County, with over 40 programs providing services in behavioral health, family and social well-being, early childhood education, housing, and more.



Psynergy

Psynergy has state-of-the-art residential treatment centers located in Morgan Hill, in Greenfield on the Central Coast, and in the City of Sacramento. Each campus is dedicated to fostering a journey back to health for people with serious mental illness. It provides a team of licensed therapists, farm-to-table meals, personalized exercise plans, and equine therapy. Psynergy allows individuals to move out of locked settings and into successful community living. *Together Achieving More* is their motto. When one enters the Psynergy campus in Morgan Hill one does not get the sense of an institution. The grounds and common areas provide a beautiful area where a person can sit and be with friends. The meals served are prepared with meticulous care at achieving both nutrition and flavor. Psynergy knows that rejoining the community is an important step to wellness. From the campus, residents can easily access shopping, restaurants and parks enjoyed by the greater community.



What sets Psynergy apart from most programs is the caliber of treatment professionals on-site. There is a resident Psychiatrist, a Psychologist, Master Level Clinicians, and well-trained Care Staff. The ratio of care providers to residents is exemplary. A resident at the Morgan Hill campus has the ability to come from a locked facility and move from a shared room to living in an apartment on-site. Each level of support comes with the needed level of care and supervision. Assessment, Plan Development, Individual Therapy, Individual Rehabilitation Counseling, Family/Collateral Counseling, Medication Support (MD and Non-MD), Crisis Intervention, and Case Management are tools used by the Psynergy team. Specialty Mental Health Clinics are co-located next door to the Adult Residential Facilities, giving Psynergy the ability to provide a higher level of care to its residents. Ninety-five percent of the residents are Medi-Cal, Medicare, SSI, or Veteran Affairs beneficiaries.

Psynergy is developing new campuses in Sacramento. When construction is complete, Psynergy will have a campus where residents can choose from different housing options which they can call home, such as living in a dorm-like setting or in their own cottage. Psynergy recognizes that while some residents will only be with them for a few months, others may live there for many years.



Oxford House Self-Run/Self-Supported Recovery Houses

Oxford House has three recovery houses located in Contra Costa County. Their mission is to help clients who have a substance use disorder with a co-occurring mental illness. Acceptance into an Oxford House begins with an interview with the house residents, and eighty percent of the house residents must agree that the applicant will be a good fit for the house. The Oxford Houses are run and supported by those who live in each house.

The residents interviewed said that the least amount of money you take from others, the more self-directed you can be. The residents emphasized the importance of being in control of their own destiny. They felt that the motto of “Recovery, Responsibility and Replication” was essential to success for each person and the Oxford House Movement. Each house is a rented, ordinary, single-family residence.



Each home operates under a charter from Oxford House which is a 501(c)(3). The charter has three conditions:

- the group must be democratically self-run following the Oxford House Manual.
- the group must be financially self-supporting.
- the group must immediately expel any member who returns to using alcohol or illicit drugs.

Residents govern themselves, elect house officers, hold regular house meetings, and pay their own way. Rent in Contra Costa County is \$750 a month and includes power, water, and electrical needs.



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Oxford House administrators, who once started out as residents, help to sustain and replicate the houses. A contract with the county also enables these administrators to keep the houses self-regulating effectively.

Oxford House is a recovery home for those addicted to alcohol and addictive drugs. There was discussion among the administrators and residents about what happens if someone relapses. Their answer was that they are immediately removed from the house. For each resident, there is a written emergency departure plan that is in place so that if a relapse does occur, their departure is done in the most supportive manner.

Contra Costa County has the most Oxford Houses in California. Oxford Houses are either all female or all male residences. The residents are hoping to expand soon with one more home for women. There are three homes now. The women's house has twelve residents and the men's houses have eight and thirteen residents. Oxford Houses have been in Contra Costa County since July 2019.





Moving Towards Housing That Heals

As two Moms on a Mission, we have assembled evidence of California's lost promise to our families and local communities.⁴⁶ We have found clear evidence of some of the most amazing programs of promise. Right now, in 2020, we have concerns about whether the State will be able to find the right leadership to guide California towards the promised land of Housing That Heals for families like ours.

We have intentionally spotlighted the WIC 5600.3(b) specialty mental health population's housing needs only. This population has been forgotten too often. We spotlight those who have been promised a right to treatment before tragedy, incarceration, institutionalization, or homelessness over and over again since the deinstitutionalization wave. We refuse to allow the current generation of this population to be forgotten any longer. Our loved ones are not *the disposables*.

We spent twelve months traveling across California to visit housing programs and attend local and state meetings. We traveled with open hearts and minds. We invited partners to join us along the way with the pure intention of developing a shared vision of hope, health, and home. While we did find hope sprinkled across the state in our travels, we must conclude by stating emphatically that *hope is not a system of care and we are determined to see California go beyond hope in 2020*.

We are grateful that housing is clearly on California's political, social, and legislative agenda in 2020. But, will it be "Housing That Heals?" And, will the State's housing agenda focus only on homeLESSness or will it recognize the need to build a system of homeFULLness for the WIC 5600.3(b) population? Will the legislative agenda replicate plans that have failed for years? Or, will it embrace the perspectives of families like ours who understand where the weakest links exist and the ways they can be fixed? Will the State focus on action instead of more meetings, missions, and mappings?

Our families expect the State to build a shared agenda and co-create a clear, collective action plan in 2020. While the current efforts in Sacramento are attempting to course correct, we must do better than aim in 2020; we need to hit the target. We believe that our research, reflections, and recommendations will help the State move beyond a *fail first*,⁴⁷ *housing first*⁴⁸ mentality that currently exists in the third world reality found in our cities, counties, and communities. We know we can do better and *must do better* in this first world country of ours. California cannot afford to wait any longer.

Our families have partnered with patience while waiting for the system to care. Families are often begging for treatment before tragedy and we are told to wait. We wait for the police to come and make a medical decision about treatment based on limited training. We wait for the health providers to feel safe enough to provide medical assistance. We wait for medical beds that are nonexistent.

We are worried that the current focus on only unsheltered homelessness, regardless of diagnosis, will force the SMI clients and families who have been waiting for the right care, at the right time, in the right place... to just keep waiting.

⁴⁶ [Appendix: A Spotlight on Contra Costa County](#) provides further discussion on the system in our home community.

⁴⁷ <https://www.propublica.org/series/right-to-fail>

⁴⁸ <https://www.manhattan-institute.org/housing-first-effectiveness>



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We cannot wait forever for the State to fix every social, climate, and political crisis while our loved ones are still “slipping away.” When will the sweeping crisis of SMI be the focus?

Our focus is purposeful. It is to use Housing That Heals as a quality improvement strategy for the SMI population. It is to move our system of treatment beds from scarcity to abundance. It is a strategy that will break the human log jam and relieve the firefighting mentality of the current system. When a “familiar face”⁴⁹ is placed in Housing That Heals, there will be less risk, less restriction, less restraints, and less suffering. There will be stability, dignity, and humanity. The models we have highlighted can and must be replicated. We need to support the quality housing and treatment providers who say “yes” to those who are hard to treat. Currently, the only beds that welcome all SMI people, regardless of diagnosis or payor source, are jail beds. This must end. We cannot promise to reduce incarceration, criminalization, and homelessness until we provide alternatives. We cannot divert from solitary confinement, higher levels of care, or more restrictive care without building bed capacity in the community. Our families want no more and no less than what any family member wants for a sick loved one. We want a full continuum of the right care, at the right time and in the right place. We want a right to treatment with dignity and a system of care to support both the medical and social determinants of health. We seek common ground to build that system of care for those who have been waiting for a chance to heal. As the State aims to fix the current crisis, the people who live heroically with an SMI must not get lost or forgotten again in the State’s human and fiscal shell game. California must address all four drivers of death, despair, and disparity that we have identified.

If we want a “Healthier California for All,”⁵⁰ then all disparities must be the focus. California must formally designate SMI as a health disparity. Health disparities are usually addressed in relationship to socioeconomics, culture, race, and gender, which are critically important. However, the definition of “unserved” and “underserved” is defined in the California Code of Regulations (CCR, Title 9) as “individuals who may have SMI and/or serious emotional disturbance and are not receiving mental health services. Individuals who may have had only emergency or crisis-oriented contact with and/or services from the County may be considered unserved.” Underserved individuals are also those “who have been diagnosed with a serious mental illness and/or serious emotional disturbance and are receiving some services but are not provided the necessary or appropriate opportunities to support sustained stability and recovery.” The definition dilemma goes beyond SMI.

The current State planning discussions have bold aims. One of the current aims under the “CalAim”⁵¹ Medi-Cal 1115 and 1915b Medi-Cal Waiver discussions⁵² is to change the way medically necessary treatment is defined. The proposal would expand medical necessity eligibility to include those who might have any mental health or substance abuse problem without having to obtain a formal diagnosis.

⁴⁹ The term “familiar face” refers to refers to a population defined as individuals who are frequent utilizers of emergency, acute, jail, crisis services. <https://www.kingcounty.gov/elected/executive/health-human-services-transformation/familiar-faces.aspx>

⁵⁰ <https://www.gov.ca.gov/2019/12/18/governor-newsom-announces-healthy-california-for-all-commission>

⁵¹ <https://www.dhcs.ca.gov/provgovpart/Documents/CalAIM/CalAIM-High-Level-Summary.pdf>

⁵² http://www.itup.org/wp-content/uploads/2019/10/ITUP_DiscussionGuideOct_101419.pdf



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This would be a shift in focus away from a diagnosis and towards a definition based more on “level of functional impairment.” With a current dearth of both hospital and community beds for both SMI and SUD, we worry how the State will create bed capacity and additional staffing capacity for an expanded population.

And, while the State studies this test of change, we worry about what will happen to the population of people who are already diagnosed with SMI, classified as disabled, and incapable of independent living. This is a population who has been waiting for access to medically necessary health care and housing. This is an underserved population that must be prioritized.

We are grateful for the current 1115 Waiver discussions to improve outcomes for all Medi-Cal beneficiaries. But, with plans to change the definition of medical necessity to allow more access for undiagnosed people while threatening another MHSA reform,⁵³ we fear that the system will implode, not improve. The MHSA was the promised funding source for the Specialty Mental Health “system transformation,” and that promise for transformation remains unfulfilled. In addition, it seems as if the California aim is to focus mostly on people who are experiencing homelessness. This is honorable. This is humanity. But, many of the current unsheltered homeless population do not have an SMI as currently defined, the way our sons’ adult lives have been defined based on a Diagnostic and Statistical Manual of Mental Disorders diagnosis and their level of disability and functioning. We do not want anyone to live unsheltered, but we worry about the system’s ability to provide adequate capacity for all of the most seriously mental ill population. We worry about those at risk of homelessness who have been waiting for quality housing and care.

If we are going to build a continuum of care, then many bureaucratic, licensing, and funding barriers must be removed for the IMDs, ARFs and RCFEs in order to scale up and save lives. The cost savings of providing the right care will support the investment. This too is prevention and intervention. And, California cannot claim to be addressing parity and discrimination while allowing the IMD Exclusion Waiver⁵⁴ opportunity to stall for the SMI population. **How can California allow the ideological tension over involuntary care to be an excuse when we use jail or prison as a system of care for the severely mentally ill population?**

In order to create a “Healthier California for All,” California must not only focus on the Medi-Cal population but put a laser focus on all public and private policies that lead people and their families off the cliff with only the public system’s mental health system as the safety net. While putting a spotlight on parity for private insurance will be helpful for future generations, the State must not abandon those already in the public specialty mental health system who have been waiting for a whole system of care to be fully funded.

⁵³ <https://www.chcf.org/blog/addressing-homelessness-high-governor-newsoms-agenda>

⁵⁴ <https://www.treatmentadvocacycenter.org/storage/documents/backgrounders/imd-exclusion-and-discrimination.pdf>



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The state legislators and Governor have rightfully called out private insurance for parity negligence. However, we must respectfully call out the State for ensuring that parity will never be achieved for the Medi-Cal population due to the funding discrimination with a Welfare and Institution Code that covers serious mental illnesses, “only to the extent resource are available.” The State must reflect on its own history of maintaining this inequity for our most vulnerable. There will never be equity or integration with minor legislative tweaks to private parity only.

California must bust funding and delivery system silos in order to provide true community integration for both SMI and SUD populations.

California must ensure that any new waivers, policies, or legislation will not incentivize a Homeless Continuum of Care or the Drug Medi-Cal Organized Delivery System to displace vulnerable SMI residents who are currently living in ARFs or Board and Cares. **For example, we have learned that one ARF owner has been offered \$1000 more per bed for unsheltered homeless individuals.** This would displace the current SMI residents who are only funded at \$35/day. To achieve an SMI Triple Aim, we must stabilize the current supply of community-based beds.

We do applaud all efforts to prevent and intervene with suffering, but we refuse to allow the current SMI adult and older adult generation to be forgotten. Those already diagnosed with SMI who are living in unregulated, substandard room and boards, locked IMDs, revolving in temporary shelters, or living with their elderly family members must not be considered adequately housed. Shelters and locked IMDs are not homes. And, we must not forget that our main question when starting this journey was “What will happen when we are gone?”

California must address this at-risk population, too. We need prevention and intervention tools for those already diagnosed “stage 4” SMI. MHSA was not just intended to only serve children or homeless populations. Both Laura’s Law and LPS Conservatorship are preventative tools that must be used when necessary in order to save lives. However, without a full continuum of psychiatric care that includes public and private hospital beds, community-based programs, and a full continuum of tiered Housing That Heals, then tweaking parity laws, reforming LPS and raiding MHSA will not prevent the crisis from growing.

We caution the state Behavioral Health stakeholders whose focus may be narrowed by age group, insurance category, or other special interest to widen your views. Will more millions of dollars spent on more of the same really make a difference? Or, do we need a whole new way of looking at whole person care across the age span for the SMI populations? Should we only focus on building community services or should we finally understand that we need to rebuild the psychiatric hospital-based system as well? There are no quick fixes. No “one size fits all” approach. But, if we are going to unclog our prisons, streets, and morgues, then we need a system of care that includes a right to shelter and a right to treatment in California. **California must lower the bar for “grave disability” and raise it higher for incarceration.**

We need a way to hospitalize those who need it and community pathways to support assisted outpatient treatment for people who do not need hospital-based care. A community system and resource allocation must be flexible to move money around for the people who need it most.



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People living with SMI are dying while elected officials and legislators have endlessly planned with good intentions but without constancy of purpose. Our state will continue to be in “condition red” until we recognize the weakest links. We know that California will not solve the homeless crisis, the justice system crisis, the emergency room crisis, and the crisis of not caring until we break common ground for a hospital and community-based continuum of psychiatric care that includes a continuum of Housing That Heals.

The data dashboards used by the State to guide improvement and measure priorities are not adequately reflecting the 5600.3(b) SMI population. We must dive deeper into the data to determine who will be helped first. Who will be forced to fail once, twice, three times... eight times at a minimum, before help is given? Who will continue to be left psychotic, homeless, and helpless? And, who will continue to be left psychotic, housed, and helpless? California has a moral obligation to ensure that BOTH of these vulnerable populations are properly housed and healed.

California must stop pitting vulnerable, disabled communities against each other all in the name of civil rights. Ideological battles must end if California is to prevent the death spiral related to serious mental illnesses. There is nothing civil or right about the data of the soul of our families and communities.

As we traveled across California, we witnessed the housing crisis explode on all levels; it has reached the tipping point. The suicide rates grew, both in and outside of jails and prisons.^{55,56,57} We saw task forces created, policies debated, and bills proposed. But, we are left to wonder if the current proposed reforms, refreshes and realignments will truly be the true north star for all. Or, will it leave the most vulnerable SMI population still reaching for a life raft while the deck chairs are being rearranged and the ship is going down? Whose moral compass will guide us forward? Who holds the keys to the locked doors? Who holds the keys to open the doors of Housing That Heals?

We are confident that we have identified four key drivers of despair and disparity that have prevented California’s ability to build a scalable, sustainable continuum of psychiatric care. These drivers have clearly contributed to the lack of access to safe, effective, person and family-centered, timely, efficient, and equitable Housing That Heals for the specialty mental health WIC 5600.3b population as currently defined. These drivers have also contributed to deaths of despair and a continuous circle of suffering.

We must all focus together on solutions that will design these drivers of despair, disparity, and death out of our California health and justice systems.

⁵⁵ <https://calmatters.org/explainers/breakdown-californias-mental-health-system-explained>

⁵⁶ <https://www.sfchronicle.com/bayarea/article/Suicides-in-California-prisons-rise-despite-14476023.php>

⁵⁷ <https://www.sacbee.com/news/investigations/california-prisons/article236991514.html>



Recommendations for Housing That Heals

We recommend the following considerations to develop a continuum of psychiatric care and Housing That Heals for the specialty mental health WIC 5600.3(b) population as currently defined in order to achieve the SMI Triple Aim in California.

1. Mandate a shared definition of serious mental illness in the medical, social justice, courts, detention, and community health delivery systems.

- California must mandate a standard shared definition of SMI, whether it be WIC 5600.3(b) or the common language Model Shared Definition.⁵⁸
- LPS Reform, Justice System Reform, and Payment and Delivery System Reform must clarify the definitions of medical necessity, grave disability, unserved, underserved with a focus on a right to treatment for SMI.
- Data must clearly be analyzed based on a shared definition of SMI. Continuous improvement cannot be measured accurately without identifying the population. You cannot collect data until you accurately define the population. Current Specialty Mental Health dashboards must be standardized across the state and provide a baseline to track all-cause mortality⁵⁹ and morbidity in all levels of care, including jail, hospitals, residential, and community.

2. End the legal fiscal discrimination codified in the California Welfare and Institution Code and Federal Medicaid Rules.

- Eliminate the Specialty Mental Health Carve Out.
- Support parity enforcement for both private insurance and in the public system. California must strike the “to the extent resources are available” language from WIC. California cannot morally point the finger at private insurance while continuing to ration access to medically and socially necessary health care to the SMI population.
- Pursue the IMD Exclusion Demonstration Waiver for the SMI population. The IMD exclusion is fiscal discrimination and raises parity issues since for no other conditions are Medicaid services in certain medical institutions excluded.
- Protect MHSA funds for the WIC 5600.3 SMI population to ensure that the most ill receive the necessary medical and social support to intervene with crisis and prevent failing in the least restrictive Housing That Heals.
- Prevent the displacement of SMI clients by incentivizing providers with higher reimbursement.
- Stop pitting vulnerable populations against each other.

⁵⁸ <https://stepuptogether.org/wp-content/uploads/2018/04/Model-Shared-Definition-of-SMI-Practical-Strategies-for-Its-Use-to-Reduce-the-Number-of-People-with-Mental-Illnesses-in-California%E2%80%99s-Jails.pdf>

⁵⁹ <https://medical-dictionary.thefreedictionary.com/all-cause+mortality>



3. Eliminate the Ideological tension by marrying the Medical Model with the Recovery Model.

- Marry the Medical Model with the Recovery Model. It is not necessary to divorce these two models of care in order to achieve optimal health for the SMI population. End the ideology wars about the right to refuse treatment if you lack the capacity to know if you need it.
- Adopt a hospitality model across the psychiatric continuum of care in both hospital and community-based systems.
- Embed family, peer, clinical, and medical supports into Housing That Heals programs. Encourage the co-location of Specialty Mental Health outpatient clinics with ARFs, and RCFEs.

4. Build a tiered level of housing and a fluid system in and out of levels of care.

- Build capacity and abundance to increase supply, quality, and outcomes. Strategically and regionally add IMD and ARF placements across the state using Housing That Heals criteria.
- Remove regulatory and bureaucratic barriers that restrict growth (e.g., remove any requirement or preferences for using nonprofits only.)
- Focus on designing tiered levels of housing across the continuum of care and age span for the SMI/SUD population. Create congregate communities of tiered care that provide clinical and social supports on-site. This will create pathways of freedom from locked units and solitary cells.

We realize that this list of recommendations may not be exhaustive of all opportunities to unclog the human log jam in California. *But it is a start, with heart.*

We are not analysts, clinicians, or administrators. We do not know all the rules, regulations and fiscal/risk analyses that policymakers must navigate. But, we are two moms who do know what it is like to beg for help, hope, and housing for our adult sons living with SMI. We do know what it like to be forced to drop private insurance in order to save our son's life. We do know what it is like to call 911 in a mental health crisis. We do know that we have been forced to make our sons homeless in order for them to receive the medically necessary care needed for their stability, safety, and sobriety. We do know the pain of blame and shame. We do know the fatigue of fighting and the fear of dying and leaving our sons without a forever home. This is why we cannot wait any longer.

“when you are forever fighting a degenerating sense of ‘nobodiness,’ then you will understand why we find it difficult to wait. There comes a time when the cup of endurance runs over, and men are no longer willing to be plunged into the abyss of despair.”

Martin Luther King Jr., Why We Can't Wait

Our families and loved ones have experienced enough “nobodiness.” We will partner with anyone who is willing to shatter the status quo and join us to build Housing That Heals, together.



Appendix: A Spotlight on Contra Costa County

Contra Costa families have been on a long mission to build a continuum of care that includes Housing That Heals for our seriously mentally ill loved ones. We have successfully built strong partnerships with our public health and safety systems, community partners, the faith-based community, and policy and decision-makers. Together we have created a vision of hope for optimal health for all. However, in spite of the best intentions and tireless efforts, we have a small, vulnerable population that needs more focus and a new way to live at home in Contra Costa County.

This heart paper is our effort to shine a light on the California housing crisis as it relates to the WIC 5600.3(b) population. We defined the problem using our drivers of disparity. We assembled some general evidence and data providing historical and current context. We traveled to nine counties covering over 3,000 miles to visit existing housing facilities.

Now, we will take that learning and combine it with our experience as both family members and authentic partners with the Contra Costa County public health system to consider the various alternatives we have seen. As residents of Contra Costa, we will give careful attention to the cost-effectiveness and the cost-benefit of the status quo, and make recommendations for immediate improvements. As moms, we will focus on value and care that must always start with heart, health, and healing.





First a Look Back: Dreams of a Residential Farm in Contra Costa for the SMI Population

In planning our itinerary for the Moms on a Mission tour, we looked back to 2001 when family members became determined that they could mobilize funding from donations to build a rural community for their loved ones. The dream was to build a supportive community made up of residents and staff that incorporated the support of families to help SMI adults achieve the most improved health, purpose, and sustained stability. This therapeutic farm might be a transitional stay for some, but for many it could become a forever home.

Under the leadership of Gloria Hill, it was amazing what this band of volunteers accomplished. By 2002, A Beautiful Night Housing Corporation (ABN) nonprofit was established through the generosity of Alameda and Contra Costa families who collectively raised over \$623,000. And, with the generosity of the Reynolds family, a 10-acre agriculturally-zoned property was purchased in Knightsen, California, a small agricultural community of East Contra Costa County, and held by ABN.

The ABN Board eventually chose Bonita House, Inc. to receive the farmland and the \$623,000. Bonita House did not realize the opposition it would face from local rural residents in applying for a use permit for the property. After a strong community outpouring of support against the NIMBYs,⁶⁰ a use permit was finally granted for 10 residents in 2011. However, some of the constraints placed on the residents, such as not having a co-occurring substance use disorder, would limit the access of many in need of this environment. Both families and Bonita House remained undeterred and approached the County's MHSA Planning process for a yearly augmentation of \$220,000/year which was granted in late 2013.

By this time, the property had been left unattended and was in great disrepair. Family members sought funding from the Community Development Block Grant program.⁶¹ With the support of Bonita House, the County Planning Commission awarded Knightsen Farm \$707,000. The County and Bonita House met to discuss increasing the ongoing programming budget in the MHSA Plan to \$330,000 in order to move forward with improvements and programming. Sadly, an accord was never reached. Today, the land remains in a broken state that mirrors the broken and unfulfilled dreams of so many families. The Los Angeles Times covered this sad story of lost hope and dreams.⁶²

In 2019, with the dream of a residential rural community still not forgotten, we remembered that one of the most dedicated family members in the early years of planning a residential farm, Mary Ellen Stuart, had found a "forever home" for her brother at the John Henry Foundation in Orange County. Her brother has since passed, but she had remained dedicated to JHF and recently had joined their Board of Directors. So, in December 2018, we reached out to Mary Ellen Stuart and planned a trip to Orange County in January 2019.

⁶⁰ NIMBY is an acronym for "not in my backyard."

⁶¹ <https://www.contracosta.ca.gov/4823/Community-Development-Block-Grant>

⁶² <https://www.latimes.com/local/california/la-me-adv-farm-20151025-story.html>



Building a Vision of Housing That Heals for Contra Costa County

As mentioned previously, we began our site visits across California using our experience as moms as our guiding north star. Our first visit to the John Henry Foundation in Orange County set the bar high. It was a model that appeared to meet the highest medical, social, rehabilitation, and quality standards. And, it was affordable, licensed, and humanity-centered with great outcomes achieved. It definitely passed the medical, social, and family standards of care criteria we wanted for our loved ones.

JHF did fit the dream ideal “Housing That Heals” model that we had in mind. The fact that the clinical care provided was both science and person-centered was a heart note. The fact that only a handful of 5150s had taken place there during the past several years was huge. The fact that residents could have their own bedrooms, allowing for privacy and dignity, was so important. And, the respect for families as partners-in-care was key. A unique feature of this program is the fact that all residents have a diagnosis on the schizophrenia spectrum. This is such an important distinction of care because the symptomology for schizophrenia spectrum illnesses are unique to other brain disorders. Therefore, a program designed for this population only is also unique and noteworthy.

It is a program that one can only access if their family can afford to pay \$3,500/month. But, is it a program that would accept a client who “did not look good on paper,” a comment that has been made about our sons? While we do understand the fiscal and legal risks of caring for this population, the stringent licensing requirements, and the right of a private owner or nonprofit to choose their residents based on their own business model, we left Santa Ana wondering if this model could be replicated for a public system of care that chooses to serve all, not some.

We plotted our path forward as follows, considering the current state of Specialty Mental Health housing in Contra Costa. We assumed that our county would be reflective of other counties.

Situation: Contra Costa County does not have sufficient Housing That Heals as part of a full continuum of psychiatric care for the specialty mental health 5600.3(b) population that we are spotlighting. All housing placements are full. Some people are being housed in placements that do not meet even the basic criteria of safety.

Background: A variety of concerns about the shortcomings of Contra Costa’s mental health system was brought forward to the County’s Board of Supervisors in 2016, when the Mental Health Commission (MHC) issued a White Paper.⁶³ The MHC White Paper was created in partnership with a broad coalition of both hospital and community-based stakeholders and offered as an improvement “tool, not a hammer.” Since the White Paper was issued, it has been the source of many community conversations, Grand Jury Reports, and Board of Supervisor hearings. As part of the original stakeholders who wrote the MHC White Paper, we support the ongoing collaborative efforts to work on the issues raised and we have also participated in those efforts.

⁶³ MHC White Paper: http://64.166.146.245/docs/2016/BOS/20160913_807/26920_White%20Paper%20-%20Signed%20by%20Duane%20Chapman%205.24.16.pdf



However, we believe that one of the most critical issues mentioned in that White Paper that has not been adequately addressed is the section entitled “Housing That Heals” (excerpt below).

Housing That Heals

The number of persons with a serious mental illness who are homeless and in county shelters is rising. All MHSF-funded supportive housing for those with a serious mental illness is at capacity and our in-patient psychiatric unit is full. There is a tremendous unmet need for mental health residential treatment and long-term supportive housing, yet we are holding millions of dollars in unspent MHSF funds.

More alternative treatment residential programs that lead to permanent, service-enriched housing models for people with serious mental illness need to be explored, invested in, and implemented. Although “Housing First” was been adopted and promoted in our county several years ago, it cannot be effectively implemented without an adequate inventory of housing that is embedded with services that support consumers in developing skills to maintain their health and recovery. A true supportive housing model that includes teaching many consumers “direct skills” to maintain their health and recovery will prevent many high costs and reduce out-of-county placements.

The housing needs of our consumers and families present many challenges that follow a continuum from least restrictive to locked settings. Some see a need for more permanent supportive and shared housing; others see a need for more shelters, while others are calling for more residential alternative treatment settings. There may be a need for all. Behavioral Health is committed to working with stakeholders to look at the whole picture and to define solutions to the housing crisis, but planning meetings without action plans that are implemented remain only a dream, not a needed solution.

Creating a well-planned system for moving those with serious mental illness into the most appropriate housing model will be a savings to the county. There will always be a need for locked facilities and skilled nursing facilities, but many patients could be more effectively served in alternative residential treatment programs and permanent supportive housing in this county. Permanent supportive housing will also give those living in shelters or transitional housing a better path to optimal health. The county budget process must take a deep look at the funding streams that could make supportive housing a reality for people with serious mental illnesses.”

The original response from the County’s Behavioral Health Services stated, “Housing and housing with treatment are complex issues. Given that housing is a scarce resource, the Behavioral Health Division organizes a number of housing committees to address the various needs of our consumers. These committee meetings solicit community stakeholder input as required by our funding stream. This includes, for example, the recent development of our Coordinated Housing Entry Program.”⁶⁴

⁶⁴ CCCBHS White Paper Clarifications:
https://drive.google.com/open?id=10HmrRodoRCSQk_he0T3w6x0luuDRnGLJ



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We understand the pressures and competing priorities that our public safety net system is experiencing. However, as former Contra Costa Mental Health Commissioners and members of our County's original MHSA Planning process, we have attended many community stakeholder meetings where housing priorities were debated. We have watched the dots put on the walls and witnessed housing being voted on as the number one system gap indicator year after year.

However, while claiming that the MHSA is a stakeholder-driven process, the wisdom of the SMI community is too often ignored and "funding streams" and political or special interest agendas seem to influence decision making. Consequently, housing opportunities were either missed or focused on short-term shelter beds and rental subsidies instead of on long-term systemic solutions.

In addition to the MHC White Paper, there was a quantitative "System of Care Needs Assessment" performed by the Contra Costa County Behavioral Health Services (CCCBHS) in 2016.⁶⁵ Using a baseline report from 1981, *A Model for California Community Mental Health Programs*,⁶⁶ the needs assessment declared that "overall, CCCBHS Mental Health is reaching the target population it is mandated to serve." The assessment recommended "that CCBHS Mental Health continue to improve its capacity to assist consumers move from higher levels of care, such as locked facilities, to lower levels of care that are community based."⁶⁷ This has been a continued discussion point in recent stakeholder meetings without a clear solution for the adult specialty mental health population.

These were not the first reports identifying the need for housing development in Contra Costa. There have been numerous previous housing reports and studies done in Contra Costa that could also provide planning guidance. The excellent 1994 report by the Contra Costa MHC could have been a great baseline report for the community planning process to use when the MHSA was being implemented beginning in 2004.⁶⁸ This report identified that 47% of the County's SMI population was living with aging family members. There are recent anecdotal claims that this is still true. This begs the question, "Is Contra Costa County adequately preparing for the inevitable increase of homelessness when our aging family members are no longer here to support their loved ones?"

Another excellent report was prepared by Contra Costa's Mental Health Consumer Concerns in 2013, *Augmented Residential Care Facility Project Report*.⁶⁹ It was vetted through the Contra Costa County MHC who recommended the report be used as a guide to be followed. That report called out the precarious state of the Board and Care Home model. Since so many people were placed outside of Contra Costa County, this report also made recommendations about the need to develop new in-county residential options and was part of what was called the "Bring 'Em Home" campaign.⁷⁰

⁶⁵ <https://cchealth.org/mentalhealth/mhsa/pdf/2016-ccbhs-needs-assessment.pdf>

⁶⁶ http://histpubmh.semel.ucla.edu/sites/default/files/archival/d8485804_Doc_7._1981_California_Model.pdf

⁶⁷ <https://cchealth.org/mentalhealth/mhsa/pdf/2016-ccbhs-needs-assessment.pdf>

⁶⁸ Contra Costa County Mental Health Commission Housing Report 1994:
<https://drive.google.com/open?id=16lzwZy9NHaBlxkH2KD75Ts1otX8j7h2o>

⁶⁹ Augmented Residential Care Facility Project Report 2013:
https://drive.google.com/open?id=19AcbkCTInelq06Q8_fs1z0hJO_Wzz9wF

⁷⁰ <https://cchealth.org/mentalhealth/mhc/pdf/2012-1107-agenda-qoc.pdf>



An excerpt from the Augmented Residential Care Facility Project Report reads:

“The number of available licensed homes for adults with psychiatric disabilities in Contra Costa County is barely holding its own. During the course of the monitoring period, Alpine Care Home in East County closed and Blessed Care Home opened. Therapeutic Residential Services on Belmont Road in Concord had just closed, and Gina’s Residential Care Home in Walnut Creek is scheduled to close. Considering the almost \$35 million spent by Contra Costa County on out-of-county placements in fiscal years 08-09, 09-10, and 10-11 (per Public Records Act request made twice in 2012 by then Executive Director of MHCC, Brenda Crawford), it is an understatement that it would be fiscally wise to develop more in-county options, such as the Bonita house therapeutic farm in Knightsen, for consumers able to live in the community and who need care and supervision.”

Additionally, in 2014, as a result of the statewide concerns regarding the oversight of MHSA funding, CCCBHS, in partnership with MHC, developed a Program and Fiscal Review Tool. This tool was a collaborative model created to ensure that services are being provided in accordance with the values of the MHSA. Mental Health Commissioners are included as part of the Review Team and all reports are vetted through the Commission. These reviews have been invaluable in supporting quality assurance, client and family-centered service, transparency, and fiscal security of the programs.

And in 2014, Contra Costa used their MHSA Capital Funds for a state-of-the-art Crisis Residential Program intended to prevent SMI specialty mental health clients from being placed in locked settings or higher levels of care unless medically necessary. This facility has provided many people the respite needed to prevent acute levels of care. However, there is no evidence that this facility has stemmed the rising human and fiscal costs in IMDs, state hospitals or jails. Or, prevented increased homelessness. Additionally, when people are discharged from all County Crisis Residential Facilities, there is an inadequate housing continuum.

♥ Heart Note from Lauren

My son was discharged from Hope House to the street. During his time on the street he turned to using methamphetamines. Because our family knew how to advocate, we pushed hard to get our son into AOT. His provider is doing everything they can, but they are hamstrung as to what they can do since he is not conserved. Because of his illness, our son seldom answers his door. He has not taken his prescribed medication in months. He does not use his Supplemental Security Income (SSI) to pay his rent; instead, he uses it to buy alcohol, marijuana, and illicit drugs.

In 2015, Contra Costa adopted Laura’s Law⁷¹ as another tool to provide evidence-based and high-level assisted outpatient treatment to prevent higher levels of care at higher costs.

⁷¹https://leginfo.legislature.ca.gov/faces/codes_displayText.xhtml?lawCode=WIC&division=5.&title=&part=1.&chapter=2.&article=9



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Part of the original plan was to set aside funding for housing to support this program. However, many of the AOT and FSP clients are not safely or appropriately housed which may lead to fewer successful outcomes.

♥ **Heart Note from Teresa**

I shared my family story with NBC Bay Area when Laura's Law was first being implemented in San Francisco and Contra Costa County.⁷² My son was lost in the shuffle of solitary confinement to state hospitals at the time. I had worked for over 10 years to get Laura's Law adopted in my home county of Contra Costa so that people could receive treatment before tragedy or torture.

One of the first clients to enter the Contra Costa Laura's Law program was a young woman named Arises, who I had come to know through her mom, Jackye. Jackye was a tenant of ours and had reached out to my husband for help when her daughter was in early psychosis. I navigated a 5150 with Jackye and helped her daughter get into a Full-Service Partnership for Transitional Age Youth. That program worked for a while, but when it stopped working, Jackye reached out to me again for help. I helped Jackye navigate the referral process for the new Laura's Law program in Contra Costa County.

This success story with Jackye was covered in a 3-part investigative series by Sheyanne Romero and the Visalia Times.⁷³ It blends the story of Arises Collins, my son Danny, and the tragic story of Linda Mudge. Linda might still be alive had she been offered Laura's Law and "Housing That Heals." We need access to both in all counties of California. Access to lifesaving tools should not depend on who you know, your zip code, or your diagnosis.

In 2017, Contra Costa experienced the same tension as other California counties over the debate to build jails instead of funding adequate diversion programs. For people who have an SMI, the primary diversion program should be AOT. The community has successfully lobbied for new innovative diversion programs for many underserved subpopulations, and our Health Services Department has partnered with the community and demonstrated a clear vision of authentic partnership and one care for all. The Rapid Improvement Events⁷⁴ focusing on the detention health services is an improvement model to be shared state and countrywide.

However, like all California counties, there is still a population that cannot be diverted to community-based programming and are left waiting for "a bed instead"⁷⁵ of a solitary cell. So, the jail debate must continue until there is truly one care for all in Contra Costa County and no one is jailed and criminalized unnecessarily. The Sequential Intercept Mapping⁷⁶ process that began in 2018 is a beginning to this end.

⁷² https://www.nbcbayarea.com/on-air/as-seen-on/Bay-Area-Mother-Takes-On-Mental-Health-Care-System_s-Revolving-Door_Bay-Area-315653531.html

⁷³ <https://www.visaliatimesdelta.com/story/news/2019/03/21/lauras-law-mental-illness-treatment-cost-tulare-county/1695063002>

⁷⁴ <https://cchealth.org/video/2017-1201-dh-report-out.php>

⁷⁵ <https://www.treatmentadvocacycenter.org/fixing-the-system/features-and-news/3661-a-bed-instead-advocacy-campaign-launches-take-the-pledge>

⁷⁶ http://64.166.146.245/docs/2019/BOS/20190514_1286/37290_SIM%20Final%20Report%20PRA%20Associates%20April%202019.pdf



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Notably, there is no mention of using the empty unit at our local county hospital, Contra Costa Regional Medical Center, that was closed in 2008. Using this unit would be a humane solution to treating the gravely disabled inmates who are now placed in "safety cells" instead of a hospital bed.

♥ **Heart Note from Teresa**

My son had been in many IMDs but was unable to successfully sustain stability once in the community until the past year. We were told that the "best" IMD in California was California Psychiatric Transitions (CPT) in Merced County. BUT... we were told that it was a higher cost contract that was not available unless you were only on Medi-Cal. We had maintained our son's private Kaiser Insurance as a disabled adult for 8 years and tried to support the horrors of juggling his private insurance and public LPS Conservatorship which often pitted one system against the other with our family stuck in the shuffle. So, we were encouraged to drop the private insurance in order to get our son access to CPT.

He was placed at CPT twice, and both times were successful. The first time resulted in a failed transition due to the community placement's failure to provide my son's injection of anti-psychotic medication. This cost him a lot.

He ended up being re-hospitalized and nobody would take him back. So, he ended up at Napa State Hospital as one of the small percentage of patients placed there on a civil, not criminal commitment. The medical care was not collaborative, the medications were wrong and my son ended up lashing out and was arrested as a patient. He was IST for four years, in and out of two state hospitals and solitary confinement in jail before being diverted back to CPT.

He soared to success and stability on his second stay at CPT. He was given the perfect combination of medication, structure, and compassionate care, allowing him to graduate for the first time from an IMD and successfully transfer to a community placement at Psynergy, Inc. in Morgan Hill. For the first time in 20 years, he was given the right amount of time to stabilize and move through the CPT levels of care. He then transitioned successfully to the community through the Psynergy model of outreach and engagement. Danny has continued his recovery process at Psynergy for a year due to their on-site clinical, medical, and recovery supports. This is prevention, intervention, and person and family-centered, value-based care.

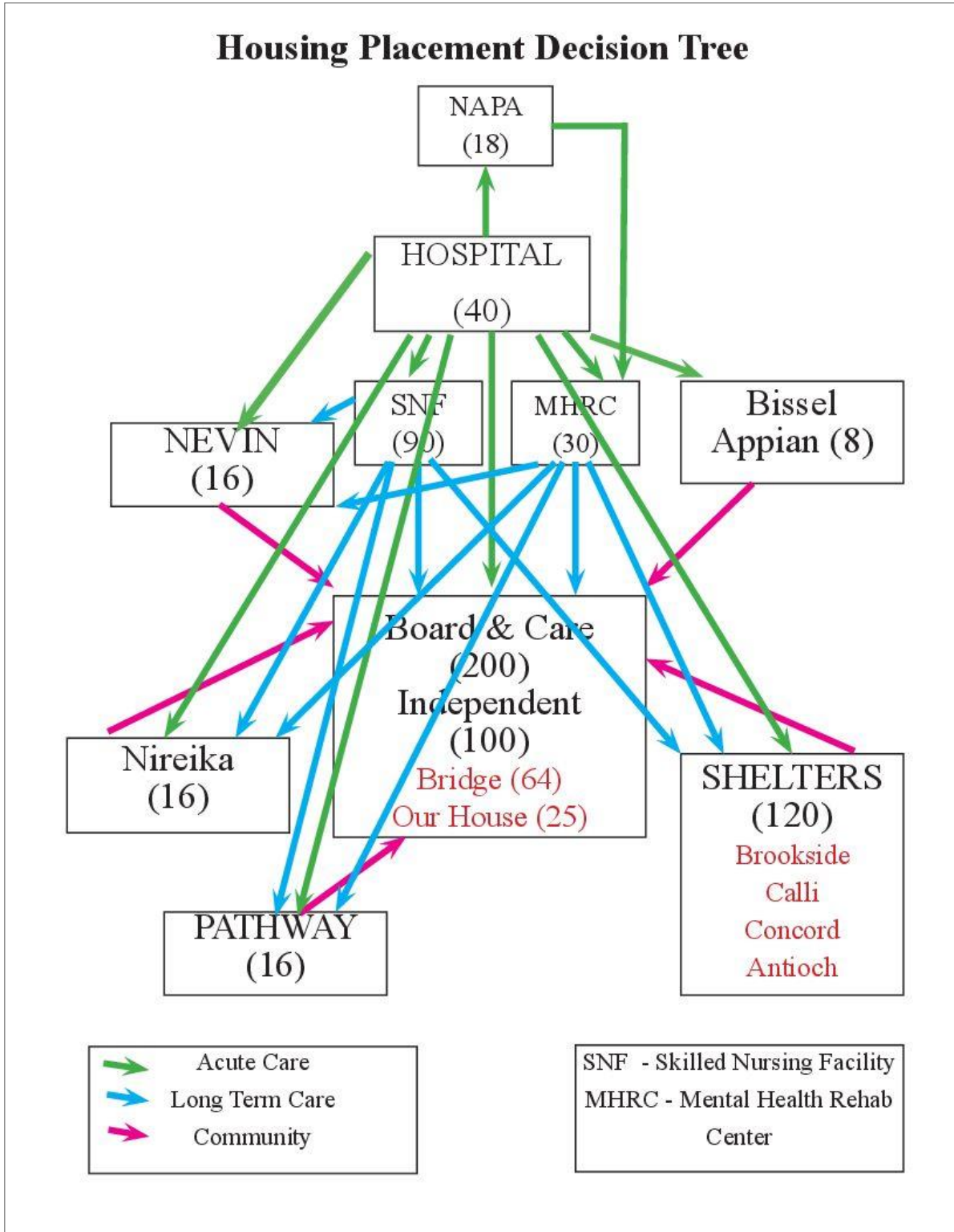
Danny would not have survived solitary confinement in jail if he had not been provided the tiered levels of both CPT and Psynergy. I consider CPT to be the gold standard for IMDs in California. CPT was the least restrictive care at that time. A locked IMD is less restrictive and more therapeutic than a solitary jail cell.

Psynergy is one of the few gold standard ARFs in California. CPT is locked. Psynergy is unlocked. My son needed CPT in order to be accepted into Psynergy. Both are what I call "Housing That Heals"

We need a both/and state of mind in California, not either/or. Medicaid should pay for both if medically necessary. No one should be forced into solitary confinement and criminalized for their illness when there are models of less restrictive care that must be used, funded, and replicated.



A search of local news articles over the past years shows a trail of lost beds, lost opportunities, and lost lives. In reviewing this local history, we located an old *Housing Placement Decision Tree* document that was publicly distributed in Contra Costa as a teaching tool demonstrating the “human log jam” that our Specialty Mental Health administrators must navigate.





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We have requested an update from Contra Costa Behavioral Health Administrators on this placement decision tree, along with additional data to inform current and future planning.

At this time, we know that a bed committee meets every week to make placement decisions based on utilization and review data. We know that our health, housing, and homelessness providers meet and discuss high utilizers of multiple systems (HUMS). We do not know how these two divisions interface. We know that there are more people to juggle and believe that there are fewer beds to place them in. However, we do not know how the Specialty Mental Health Services (SMHS), Alcohol and Other Drug Services, and Health, Housing and Homelessness (H3) services intersect when beds are prioritized. This begs many questions.

Who are the “bed keepers?” What drives the decision making for the specialty mental health population in Contra Costa or any California county? Who is at the table and how is it decided who gets a bed, when and which bed? Are Conservators present? What role do they or case managers play? Does the patient or family have any choice in the placement? Are bed decisions based on the person’s clinical needs, their capacity, or their past experiences? Is it program-based, value-based, funding-based, or diagnosis-based? Or, is it based on who you know, who is at the table, or who has the best pitch for their patient that day? We feel that the answers to these questions should be public knowledge.

We do believe that in order to know if a housing program is healing, it must have the ability to continuously connect to a system of care that meets the Institute of Medicine’s six quality aims⁷⁷ and measurable outcomes. These six aims must not only be recognized quality standards of care for hospital and community-based care for serious mental illnesses, they should also apply to the essential health element of housing for this vulnerable population.

There should be a standardized, transparent process that is not system-centered or based on luck and heroics. However, that would require a full continuum of Housing That Heals based on “abundance, not scarcity.” And, that simply does not exist in any California county. There must be equal standards of care for physical illnesses and brain illnesses. They must be based on both science and a “Family Standard of Care.” Just as the Cancer Center of America has established the *Mother’s Standard of Care*⁷⁸ test, Housing That Heals in California must not just be an open bed that a care provider or insurance company designates appropriate. It must also be a bed that any family member would want for their own child, mother or loved one.

While the Housing First model⁷⁹ claims success based on few restrictions or criteria, Housing That Heals must first include treatment and stability supports appropriate to the resident's current needs but also considers future potential needs.

Housing That Heals is a lifespan plan for those who live with serious mental illnesses.

⁷⁷<http://www.ihl.org/resources/Pages/ImprovementStories/AcrosstheChasmSixAimsforChangingtheHealthCareSystem.aspx>, <https://www.ahrq.gov/talkingquality/measures/six-domains.html>

⁷⁸ <https://www.cancercenter.com/become-a-patient/patient-experience/mother-standard-of-care>

⁷⁹ <https://endhomelessness.org/resource/housing-first>



Assessment of Site Visits

In this assessment, we will do a selective analysis of some of the facilities that we visited across the state using our experience with the Contra Costa County public mental health system as our context. Our intention is that this assessment will be applicable to other county systems.

We propose the following adapted *Housing That Heals* Criteria for the 5600.3(b) specialty mental health population of Contra Costa County to ensure quality standards of care:

1. **Safe:** The public mental health system will provide safe Housing That Heals that is clean, comfortable, clinically appropriate, and secure.
2. **Effective:** Housing That Heals will include evidence-based, medically-necessary supports that will offer continuous access to BOTH clinical care and social rehabilitation needs.
3. **Person and Family-Centered:** Housing That Heals will offer a stable living environment that allows personal choice that meets the individual's medical, cultural, social, and spiritual needs and abilities.
4. **Timely:** Housing That Heals will be immediately available to all of the 5600.3(b) public health specialty mental health population without waiting at higher or lower levels of care than is medically necessary.
5. **Efficient:** Housing That Heals will be available in a fluid, flexible system and in conveniently accessible locations based on the resident's clinical and family supports. Housing That Heals will reduce suffering before costs. Least restrictive care is not necessarily the best, appropriate, nor cost effective.
6. **Equitable:** Housing That Heals will be free of discriminatory restrictions based on race, culture, ethnicity, sexual orientation, diagnosis, or history while untreated.

The current state of Contra Costa's specialty mental health system of care will demonstrate that our county has a wide range of community and hospital-based Mental Health programs which are considered essential programs for a quality continuum of psychiatric care. These programs include:

- Psychiatric Emergency Service at Contra Costa Regional Medical Center
- Psychiatric Inpatient Unit
- Shelter Beds
- Crisis Residential Facilities, Hope House, Nevin House, Nierika House
- Federally Qualified Health Centers
- Regional Specialty Mental Health Clinics
- AOT/ACT Fidelity Model, Mental Health Systems Provider
- FSP partial ACT programs, Hume Center, Mental Health Systems, Familias Unidas
- Putnam Clubhouse
- RI/Wellness Cities
- NAMI Contra Costa Voluntary Family Support Network
- Coordinated Entry System through a separate Housing, Homelessness and Health Division



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While this is not an exhaustive list, it is reflective of what many SMI advocates consider the gold standard. However, even with this robust system of care, we assume that the largest psychiatric facility in Contra Costa County is still its Detention Facilities. And, we know that we have many people in out of county placements in locked IMD facilities that are not brought home because there is insufficient capacity in lower levels of appropriate care because all appropriate housing placements are full.

When we returned to Contra Costa from Santa Ana, we created a road map for the programs that we wanted to visit both in and outside of our county. We intentionally set out to visit a variety of housing programs. We knew that there was going to be a new wave of funding and focus on housing in 2019 because of the NPLH⁸⁰ initiative. We knew that initiative was going to be focused on a Housing First model to address our county's "homelessness" crisis. We feared that the new planning might leave out those with SMI who were at risk of homelessness, stuck in a county jail, in an unlicensed or unregulated board and care or an out of county placement. This is the population who are often forgotten because they are currently "housed" or they have a negative clinical history that prevents access to some programs.

♥ **Heart Note from Teresa**

My son's only "Housing First" independent living situation was following six weeks of being homeless. Upon renewal of his LPS Conservatorship, the judge agreed to allow him to live in a duplex with his girlfriend who was in an FSP. It was not a safe neighborhood. The "whatever it takes" services were inadequate for their level of need. Within 3 weeks my son was off his meds and suicidal. His girlfriend called the FSP 24/7 phone line for help but nobody answered. So she called me and told me that my son was carving on his own throat. I called 911. By the time I arrived, the ambulance was pulling away and I was assured he was okay. I went inside to speak to his girlfriend and introduced myself to the Richmond Police Officer. The officer told me that when they arrived, Danny tried to run out of the house and was cornered in the back of house. He wrestled with an officer and had to be tasered. I apologized to the officer and explained the efforts we had made to support our son and the placement. I knew we were lucky that he was on his way to a hospital instead of jail or the morgue. So, this "Housing First" experiment resulted in a system failing for my son again. He returned to live in a locked facility for several months.

♥ **Heart Note from Lauren**

My son's many "Housing First" attempts have all ended the same way; the police have had to intervene with a 5150. These events have traumatized our entire family. Our family was in shock when we saw the words "cremate me" written on his refrigerator and learned of his being delivered to a hospital emergency department in a comatose state. However, the saddest thing was to learn that a Hearing Officer, after our son was an inpatient for less than one week, had deemed our son no longer a danger to himself or others and released him.

⁸⁰ http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201720180SB1206



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Our mission was to ensure that all of the SMI specialty mental health population's housing needs would be considered in all housing priority discussions. We knew that our sons would not show up on a *point-in-time count*⁸¹ but we wanted them to count. And, we knew that the Housing First model had not been successful for our sons.

We have already described our site visits in detail in the first part of this paper. Now we will apply the criteria that we would use as moms in search of Housing That Heals for our sons to the following Contra Costa County programs and include suggested solutions for improvement:

1. **Kirker Court** is a **safe** apartment community with pristine grounds. It is a **person and family-centered** facility located next to the faith community who donated the land upon which the community sits. For residents who are able to live here in total independence, these residences are **efficient**, conveniently located in an area where daily life needs are within walking distance. Kirker Court also has a ten-year wait list; this points to **stability** that is provided to the residents. The resident we spoke to wanted to re-establish a relationship with his case manager. Case managers can help provide necessary supportive services for many who live with a serious mental illness, so the **effectiveness** of housing for the SMI population at Kirker Court depends on whether they are connected with the supportive services they need. Kirker Court has an oasis-like feeling similar to the John Henry Foundation. However, it serves a different population and does not include the same clinical supports as JHF. Kirker Court is more of an independent living environment for people with any disability that falls along the moderate spectrum.

Solutions

- A nonprofit housing corporation or developer should be identified who could start development on a permanent supported housing community like Kirker Court. Master leases with the treatment provider would ensure the owner of the property a secured revenue flow and would allow people with poor financial and criminal justice history to acquire housing.
 - Contra Costa County needs to work with a provider to secure a braided funding stream⁸² that could build a complex that contains the 4-plex model outlined in the NPLH.⁸³
2. **Garden Park Apartments**, whose provider is the nonprofit organization, Hope Solutions, has developed a model of converting a rundown apartment complex into an oasis for families. Hope Solutions has used MHSA funds to build a Community Center that anchors the complex where all of the clinical services needed to support the residents are located. This model is **safe with locked gates**. The Community Center on-site allows both mothers and children **efficient** and **effective** access to licensed mental health providers in a **timely** manner. There are educational programs that support family life and enrich the future of both the children and mothers who live there. This residential program gets a gold star when it comes to being **person and family-centered**. The only problem is that so many more programs and residential opportunities like this are needed.

⁸¹ <https://cchealth.org/h3/coc/pdf/PIT-report-2019.pdf>

⁸² <https://www.tfah.org/wp-content/uploads/2018/01/TFah-Braiding-Blending-Compendium-FINAL.pdf>

⁸³ <https://www.hcd.ca.gov/grants-funding/active-funding/nplh.shtml>



Solutions

- This model needs to be duplicated for SMI 5600.3(b) adults between the ages of 25-65. Using available MHSA funds to build a Community Center provides access to **effective, person and family-centered care** that is **efficient**. The **Psynergy Program**, described earlier in this document, is an excellent comparable model.
3. **Mental Health Systems (MHS)** has used master leasing to supply Temporary Supported Housing to their AOT clients. The homes are owned by private investors who then lease the homes to MHS. Master leasing is important in that it secures a placement for an AOT client who would not be able to secure a lease. At the Antioch house, the neighborhood was **safe** and secure. The house in Pittsburg did not seem to be in as safe of a location. Residents in that home would have to be street savvy; however, many of the Pittsburg home's residents were from this area originally.

MHS secures a monthly allotment from each of the AOT residents. This allotment, in most cases, is a portion of the AOT residents' SSI. This also includes food, housekeeping, and direction on life skills. This is both an **effective** and **efficient** manner to encourage AOT clients to gain the skills needed to re-enter the community. The AOT staff hold **patient-centered** support groups at the homes.

Solutions

- In order to ensure that the houses will always be available to the AOT program, an entity – either MHS or another nonprofit housing corporation – should be the owner of these homes. The County should work with the Planning Commission, the Department of Conservation and Development, and the AOT Provider to ensure that this housing is financed in a manner that secures housing for the sole use of those with a serious mental illness. Master leasing, where the owner of the property has a commitment to the SMI population, is essential.
 - AOT and FSP providers need to have their housing located in a contained area within the greater community. An ideal set up would mirror the Garden Park Apartments where a Community Center provided access to the therapeutic supports needed. Clinical counseling supports, life skill training, and meaningful daily activity supports will always be accessed easily by the residents, and the AOT and FSP providers would also have a consistent open line of communication with their clients.
4. **Crestwood Pleasant Hill** has partnered with CCCBHS to serve individuals who are affected with severe mental illness. The location of the program and facility within the county allows those living there to be located near their **families** and enjoy access to the vibrant **community** that surrounds the facility. Poets' Corner is one of the most sought-after communities because of the **safety** and **security** it provides along with the opportunity for individuals to engage in **cultural, social, and educational opportunities embedded** in this community. Residents have the opportunity to complete their high school requirements, enroll in the nearby Community College, and seek employment opportunities in the neighborhood. This stable living environment is not always available to those who might benefit from it because it is full. Others may not fit the profile of a client that is accepted because of their past diagnosis or history.



Solutions

- Both families and consumers had to stage a massive resistance to the Nimbyism the community presented when Crestwood sought a Use Permit. There is still this archaic belief within Contra Costa communities that those living with a serious mental illness will create an unsafe environment in their neighborhood. Nimbyism must be eradicated and the benefits of having neighbors who are facing the challenges presented by serious mental illness must be understood and championed. There is a large population of people receiving treatment for serious mental illness at our County clinics and in privately insured clinics that would benefit from programs and housing opportunities like those provided at Crestwood Pleasant Hill.
5. **Family Courtyard** is a licensed board and care provider, contracted by the County, to care for adults 60 years and older. Many of the residents are very frail because of additional medical issues and needs. This facility is tucked away off of a busy business corridor next to a private high school and allows residents to have their care needs met within the community. The facility does provide a **safe** environment that is clean, comfortable, and **secure**. When family advocates pointed out a lack of social rehabilitation and supportive services, the County did step in to provide additional opportunities to participate in meaningful activities by providing classes led by trained county staff.

Solutions

- For the older adult population social rehabilitation is especially necessary. It is good that the CCCBH provides additional staff to conduct group activities that prevent loneliness and inhibit the onset of depression. These group classes such as craft and art therapy need to be a daily activity. The staff of Family Courtyard needs to be supplemented by staff who are well trained in providing the needed rehabilitative supports.
 - Older adults who have had more than one stay at the county shelter system need to be provided an opportunity to live in an assisted living community where supportive services are available to meet their mental health needs.
 - Older adults who live in locked settings should be evaluated to see if their mental health needs could be met in an assisted living community dedicated to seniors where supportive services are provided every day.
6. **Oxford House**, also contracted by the County, is a room and board that is democratically run by the residents in each house. Each house represents a remarkably effective and low cost method of preventing relapse. The homes are located in **safe** neighborhoods in the central Concord area. Residents in the home are committed to living in a **secure** environment, free of addictive substances. Residents enter the home with an emergency exit plan that ensures if they relapse an **effective** rehabilitative plan is in place. The goal of Oxford House is to replicate itself once there becomes a wait list for placement. Residents may choose to stay for a limited amount of time or for a lifetime; however, each house council may ask a house member to leave if they are a disruptive member of the house community.



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To sustain growth and to ensure that all houses stay on track, Oxford House World Services organize houses into mutually supportive local chapters and state associations – all democratically self-run and self-supported. To date there are over 2,400 houses.

Solutions

- CCCBHS must encourage Oxford House to expand in each area of the county. People with SMI and a co-occurring SUD need to have a placement available where substance abuse is not tolerated as it is in the “Housing First” model and the “harm reduction” philosophy which allows residents to stay in their housing while using addictive substances.



Recommendations to Contra Costa Health Services, Contra Costa Mental Health Commission, and All Community Stakeholders:

We are encouraged by recent efforts of our County Behavioral Health leadership to join us on two site visits and consider housing and program options such as Psynergy and Ever Well. We are hopeful that we will see a tightly-scoped formal analysis in the coming months that addresses the housing gaps for the adult SMI specialty mental health population of Contra Costa.

We ask that the following recommendations be considered as our community continues to work towards solutions for Housing That Heals:

1. Convene a *Value Stream Mapping Event* to co-create a community *Action Plan* that will focus on building increased access to a full continuum of care with all levels of Housing That Heals for the 5600.3(b) adult SMI population.
 - Review recommendations from previous Contra Costa County Housing Reports (1994 & 2013) cited in this paper along with recent reporting, housing needs assessments, and housing goals developed by California Mental Health Boards and Commissions and the California Mental Health Planning Council.
 - Perform a cost benefit case study analysis for high cost users of Specialty Mental Health Services. Focus on access to clinically appropriate level of care, not the least expensive or least restrictive. Allow a person the ability to move within the continuum of care and seamlessly access more intense levels of support, treatment when needed, and a less restrictive care environment when ready.
 - Consider the need for an in-county IMD/MHRC/PHF facility. Consider the cost to clients, families, conservators, and case managers who travel to out-of-county placements.
 - Assure equity of access to addiction treatment and primary care for all those who meet the 5600.3(b) definition.
 - Establish quality assurance standards on all 5600.3(b) housing programs. Improve care coordination and transitions to community-based care and include community oversight, accountability, and transparency.
2. Appoint a Contra Costa Behavioral Health Housing Czar/Chief who has in-depth experience with housing development, proposal and grant writing, and knowledge of the 5600.3(b) Specialty Mental Health system of care.
 - Serve as a liaison to all county departments, divisions, and community-based organizations.
 - Develop contractual relationships with multiple providers to develop a system of abundance, quality, safety, stability, and choice across the life span of a person.
 - Oversee quality assurance standards. Ensure that every member of a “care team” receives the training and education required to ensure high quality treatment and that all Department of Labor regulations are being met.
 - Track the progress of the *Action Plan* with public monthly updates to community partners.
 - Support and advocate for legislation that will increase funding to build Housing That Heals for those living heroically with a serious mental illness.



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The intention of this spotlight on Contra Costa is to provide an overview of our community's Specialty Mental Health system of care with a focus on quality housing access. We have great pride in the public health system of Contra Costa and in no way want to diminish the hard work of our community stakeholders and county partners.

We believe that we have one of the best public safety net systems in the state and nation. However, like all other counties, we have failed to bend the harm curve and provide adequate housing solutions for this most vulnerable SMI specialty mental health population. And, there is still no agreement on who the most vulnerable population is or the public data to identify it.

The mission of Contra Costa Health Services is "to care for and improve the health of all people in Contra Costa County with special attention to those who are the most vulnerable to health problems."⁸⁴ As two moms who have worked with pride and purpose to support this mission, we urge all community partners to spotlight the specialty mental health population of Contra Costa and include the WIC 5600.3(b) population among the most vulnerable to health problems.

We believe in the power of partnership and in our community's ability to unite in humanity around injustice, inequity, and discrimination. But we worry about the endless processing, papering, and planning while people with a serious mental illness are dying slowly, with their rights on.

Too many are still dying far too young due to co-morbidities, suicide, solitary confinement, and shame. While science and medical research pursue prevention and more effective treatments, we must fund proven practices today for those who cannot wait for more politics and broken promises. **We have talked enough and studied enough and we know what to do.**

Together, let us build a system of care that includes Housing That Heals in Contra Costa County.



***This Heart Paper is dedicated to all of the
♥ Moms on a Mission for Families Like Ours ♥***

⁸⁴ <https://cchealth.org/healthservices>

Beyond Beds

The Vital Role of a Full Continuum of Psychiatric Care



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Beyond Beds: The Vital Role of a Full Continuum of Psychiatric Care

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NASMHPD.org/content/tac-assessment-papers
TreatmentAdvocacyCenter.org/beyond-beds



EXECUTIVE SUMMARY

Nearly 10 million individuals in the United States are estimated to live with a diagnosable psychiatric condition sufficiently serious to impair their personal, social, and economic functioning. Hardly a day goes by without a study, headline, court case, or legislative action calling for reforming the mental health system to better serve this population. Often, these calls to action end in two words: “More beds.”

Largely missing from the outcry are answers to broader questions such as these:

- ◆ *What do we mean by “beds”? More precisely, what types of beds are needed: acute, transitional, rehabilitative, long-term or other?*
- ◆ *Are there differences in the needs of different age groups – youth, adults, older persons – and diagnoses that need to be reflected in the bed composition?*
- ◆ *What are the evidence-based outpatient practices that would reduce bed demand by reducing the likelihood that a crisis will develop or by diverting individuals in crisis to appropriate settings outside of hospitals?*

Beyond Beds: The Vital Role of a Full Continuum of Psychiatric Care addresses these questions and offers 10 public policy recommendations for reducing the human and economic costs associated with severe mental illness by building and invigorating a robust, interconnected, evidence-based system of care that goes beyond beds. Each recommendation is drawn from data and observation and is illustrated by the story of the fictional Taylor, a representative young adult whose journey toward mental health recovery illustrates both the failings and the potential of the current continuum of psychiatric care.

Beyond Beds also launches a year of National Association of State Mental Health Program Directors (NASMHPD) publications reporting on aspects of psychiatric care that together can enhance the capabilities of a robust continuum. These include a review of comprehensive U.S. inpatient capacity, forensic bed capacity and number of beds; health integration and co-occurring substance use disorders; populations with intellectual and developmental disorders and other special needs; crisis intervention; homelessness; trauma-informed care; peer services; and health disparities and cultural competence. Each assessment is grounded in the premise that people with serious mental illness need and deserve access to the same levels of care that individuals with other medical conditions already commonly experience and that obstacles to such treatment need to be removed.

To lay the foundation for the detailed stakeholder recommendations that conclude each of these papers, policymakers at every level should take the following steps:

Recommendations

Recommendation #1: The Vital Continuum

Prioritize and fund the development of a comprehensive continuum of mental health care that incorporates a full spectrum of integrated, complementary services known to improve outcomes for individuals of all ages with serious mental illness.

Recommendation #2: Terminology

Direct relevant agencies to conduct a national initiative to standardize terminology for all levels of clinical care for mental illness, including inpatient and outpatient treatment in acute, transitional, rehabilitative, and long-term settings operated by both the public and private sectors.

Recommendation #3: Criminal and Juvenile Justice Diversion

Fund and foster evidence-based programs to divert adults with serious mental illness and youth with serious mental illness or emotional disorders from justice settings to the treatment system. These programs should operate at all intercept points across the sequential intercept framework and be required to function in collaboration with correctional and other systems.

Recommendation #4: Emergency Treatment Practices

Monitor hospitals for adherence to the Emergency Medical Treatment and Labor Act in their emergency departments and levy sanctions for its violation, including the withholding of public funding. Hospitals with licensed psychiatric beds that refuse referred patients should similarly be sanctioned if monitoring shows they have a record of refusing referred patients without legitimate cause.

Recommendation #5: Psychiatric Beds

Identify those policies and practices that operate as disincentives to providing acute inpatient and other beds or that act as obstacles to psychiatric patients' accessing existing beds (e.g., the institutions of mental disease exclusion) and require hospitals benefiting from taxpayer dollar investments to directly provide or ensure timely access to inpatient psychiatric beds.

Recommendation #6: Data-Driven Solutions

Prioritize and fully fund the collection and timely publication of all relevant data on the role and intersystem impacts of severe mental illness and best practices.

Recommendation #7: Linkages

Recognize that the mental health, community, justice, and public service systems are interconnected, and adopt and refine policies to identify and close gaps between them. Practices should include providing "warm hand-offs" and other necessary supports to help individuals navigate between the systems in which they are engaged.

Recommendation #8: Technology

Create and expand programs that incentivize and reward the use of technology to advance care delivery, promote appropriate information sharing, and maximize continuity of care. Policymakers should require as a condition of such incentives that outcome data be utilized to help identify the most effective technologies, and they should actively incorporate proven technologies and computer modeling in public policy and practice.

Recommendation #9: Workforce

Initiate assessments to identify, establish, and implement public policies and public-private partnerships that will reduce structural obstacles to people's entering or staying in the mental health workforce, including peer support for adults and parent partners for youth and their families. These assessments should include but not be limited to educational and training opportunities, pay disparities, and workplace safety issues. The assessments should be conducted for the workforce across all positions.

Recommendation #10: Partnerships

Recognize the vital role families and non-traditional partners outside the mental health system can play in improving mental health outcomes and encourage and support the inclusion of a broader range of invited stakeholders around mental illness policy and practice.

BACKGROUND

That access to psychiatric beds is a topic of national urgency is an understatement.

Emergency physicians regularly issue grim reports on the boarding of psychiatric patients in emergency departments (EDs), and states are being sued—sometimes repeatedly—over bed waits. In the academic literature and mass media, psychiatric bed shortages are often blamed for homelessness, mass incarceration, mass violence, and a host of other individual and societal consequences. At times, it can appear there is no poor outcome or social system failure that cannot be attributed to the number of psychiatric beds in general, the number of state hospital beds in particular, and the trend known as deinstitutionalization.

The National Association of State Mental Health Program Directors (NASMHPD) is a membership organization of the state executives responsible for the nation's public mental health delivery system, including state hospitals. In the current environment, NASMHPD is frequently asked questions like these:

- ◆ How many psychiatric beds exist in the United States, where are they, who operates them, and who do they serve?
- ◆ How many psychiatric beds does the nation need, of what kind and where?
- ◆ What is the quality of care in these inpatient settings, and what are the outcomes they produce for patients, staff, and the public?
- ◆ Why do states continue eliminating psychiatric beds (or why are they not creating more) if these beds are in short supply?
- ◆ To what degree can homelessness; mass incarceration; violence—including suicide and homicide—substance use disorder prevalence; and a host of other clinical, social, and public health issues be attributed to the number of psychiatric beds available?

Authoritative answers have been hard to come by. No government agency publishes a comprehensive national census that includes all categories of available mental health beds—child/adolescent, adult and geriatric, forensic, public and private, crisis and rehabilitation, mental health and substance use, and all the others that serve patients with behavioral

health conditions (see Figure 1). No evidence-based target number exists for how many psychiatric beds are needed at each level of care, either in the United States or elsewhere. Causality between deinstitutionalization and social trends that developed in the same time frame (e.g., increased incarceration and homelessness) is complicated by so many confounding factors that it is never beyond debate. At the same time, a consensus definition of “psychiatric bed” that would make answering any of these questions easier does not exist.

As crucial as these questions and their answers are, what is too often lost in the clamor surrounding them is the reality that 24/7 inpatient care represents only a single component of a well-functioning continuum of care for any life-threatening health condition. We readily acknowledge that patients with cancer, stroke, congestive heart failure, and an endless number of

WHY BEYOND BEDS?

The Vital Continuum

Timely and appropriate supports are the first line of mental health care. When fully realized, they reduce the demand for the inpatient beds which provide essential backup when psychiatric needs cannot be met in the community.

RECOMMENDATION: *Policymakers should prioritize and fund development of a comprehensive continuum of mental health care that incorporates a full spectrum of integrated, complementary services known to improve outcomes for individuals of all ages with serious mental illness.*

other medical conditions may require hospitalization at some point, but we do not expect hospitals to provide all the care required for those patients to survive and recover.

Indeed, the U.S. health care system generally has moved to a model that prioritizes the swiftest possible return to the medical patient’s natural environment. From 2005 to 2014, the total number of hospital stays for all causes fell by 6.6%; for mental health/substance use conditions, hospital admissions rose by 12.2% in the United States—the only category of hospitalization that increased in the time period.¹

Figure 1: Estimated U.S. Psychiatric Bed Availability

U.S. Psychiatric Beds by the Numbers	
1955	558,922 – inpatient psychiatric beds in state hospitals (peak year; 337 beds per 100,000 population)
2014	37,209 – inpatient psychiatric beds in state and county hospitals (11.7 beds per 100,000 population, of which 17,046 or 5.4 beds per 100,000 population are occupied by forensic patients)
	30,864 – inpatient psychiatric beds in general hospitals with separate psychiatric units (9.7 beds per 100,000 population)
	24,804 – inpatient psychiatric beds in private psychiatric hospitals (7.8 beds per 100,000 population)
	8,006 – inpatient psychiatric patients in medical/surgical “scatter” beds (2.5 beds per 100,000 population)
	3,124 – inpatient psychiatric beds in Veterans Affairs hospitals (1.0 beds per 100,000 population)
	3,499 – inpatient beds in other specialty mental health centers (1.1 beds per 100,000 population)
TOTAL	101,351 – inpatient psychiatric beds (29.7 beds per 100,000 population)

U.S. Residential Care Beds by the Numbers	
2014	41,079 – residential treatment beds in residential treatment centers (12.9 beds per 100,000 population)
	183,534 – inpatients in nursing homes with diagnosis of schizophrenia or bipolar disorder (57.8 beds per 100,000 population)
2017	Bed numbers not reported by public agencies
	Child/adolescent beds, total public and private
	Geriatric beds, total public and private
	Acute-care mental health beds, total public and private
	Residential treatment beds specialized in transitional services, public and/or private
	Residential treatment beds specialized in rehabilitation services, public and/or private
	Residential treatment beds specialized in long-term services, excluding nursing homes
	Group-living beds, total public and private
	Supported housing beds, total public and private
	Psychiatric emergency room beds

Source: Substance Abuse and Mental Health Services Administration. (2014). *2014 national mental health services survey*, Tables 2.3 and 2.3.
Retrieved from https://www.dasis.samhsa.gov/dasis2/nmhss/2014_nmhss_q.pdf

Prior to the late 20th century, the psychiatric hospitals operated by the individual states essentially were the U.S. mental health system. In 2014, NASMHPD issued *The Vital Role of State Psychiatric Hospitals* to examine and affirm the continuing place of state psychiatric hospitals in the continuum of recovery services for this population.

However, the era of state mental health authorities' holding the keys to the system is over. Today, private providers, public agencies serving specific subpopulations, managed care organizations and other insurers, courts and other justice stakeholders, corrections systems, community partners such as faith-based organizations, policymakers and budgeters at every government level, special interest advocacy groups, and of course, the individuals living with serious mental illness themselves influence, fund, oversee, provide, or participate in mental health service delivery and recovery.

The opportunities and options for improving mental health care have perhaps never been greater. The Mental Health Parity and Addiction Equity Act, the Comprehensive Addiction and Recovery Act, the 21st Century Cures Act, and other federal and state initiatives have been enacted largely in response to growing recognition by the public and policymakers that inefficient and ineffective care delivery is costly, and that discriminatory practices produce poor outcomes for a large and vulnerable population. Nonetheless, consensus on priorities, strategies, and steps to achieve this end has proven elusive. In this debate, few subjects have been as fraught as the issue of psychiatric beds.

In Search of a Definition

Despite cries for more of them, the term "psychiatric bed" has no commonly recognized definition.

In the most basic sense, a bed is a place where an individual can sleep at night, but that definition relates more to housing than to treatment. After all, jails report bed numbers, too.

TERMINOLOGY

Shared terminology for core components of mental health care is essential to discussing, defining, and establishing an evidence-based continuum. Standardized definitions in American Society of Addiction Medicine (ASAM) level of care guidelines for substance use and the Level of Care Utilization System (LOCUS) for psychiatric and addiction services are examples that model the benefits to clinicians, patients, and researchers of using a common language.

RECOMMENDATION: *Policymakers should direct relevant agencies to conduct a national initiative to standardize terminology for all levels of clinical care for mental illness, including inpatient and outpatient treatment in acute, transitional, rehabilitative, and long-term settings operated by both the public and private sectors.*

In the behavioral health world, beds were once defined principally by their location inside state hospitals. The term "psychiatric bed" continues to be used interchangeably with "state hospital bed," and also generically, as if all beds serve the same purpose. Yet, most mental health beds in the United States today are located outside state hospitals, and they serve a variety of purposes for distinct subpopulations, critical distinctions that are often lost in the larger beds narrative. Beds that provide the around-the-clock psychiatric nursing and psychiatric care once found only in state hospitals now also exist in university and community hospitals, charity and for-profit hospitals, private facilities dedicated entirely to mental health care, and other configurations. Patients such as older persons with dementia who once were housed almost exclusively in state hospitals now are accommodated in a variety of community settings. Persons with substance use challenges are often treated in

facilities to address their specific needs. To further complicate matters, treatment services and a place to sleep are often delivered in the same setting, such as nursing homes and supported housing, a dual purpose that is often missed in the beds conversation. Similar overlaps are seen in the child/adolescent behavioral health and welfare systems.

Beds where psychiatric care is delivered also exist outside hospital psychiatric units altogether:

- ◆ Crisis stabilization beds for a level of care short of hospitalization, generally for very brief lengths of stay (several hours to a few days)
- ◆ Transitional or respite beds in residential or other settings for 24-hour non-medical monitoring and significant supports, typically for a fixed or limited period following hospitalization
- ◆ Long-term beds in group living environments or adult foster care settings, board-and-care facilities, nursing homes and a variety of other placements for individuals with chronic mental illness who are not ready or able to reenter the community
- ◆ Jail or prison hospital beds operated by correctional systems for incarcerated individuals with mental illness, along with placements for youth in the delinquency system
- ◆ “Scatter beds” where psychiatric patients are treated in hospital medical-surgical and pediatric units²

These bed descriptions recognize functional differences and durations of stay, but funding also differentiates and complicates the examination of psychiatric beds. When virtually all psychiatric beds were in state hospitals, they were often called “public” beds because they were funded by state budgets. In today’s world of managed care contracts and expanded Medicaid coverage, where psychiatric care in private settings may be provided through public insurance, the phrase “public bed” is antiquated, and even the notion of “publicly funded” can be problematic.

When a child/adolescent or adult bed in the psychiatric unit of a for-profit private, hospital is occupied by a patient whose treatment is publicly insured by Medicaid or Medicare, is that a private or public bed? The lack of a shared language for discussing psychiatric beds and the historical scarcity of comprehensive data about them has immeasurably complicated and obscured our understanding of the beds, their numbers, and their role in the continuum of psychiatric care.

Beyond terminology, philosophical differences also bedevil the beds conversation. More than 50 years after deinstitutionalization began, bed critics continue to fear that bed expansion on any scale could precipitate a return to the 19th-century model of institutional care that peaked in 1955. At the same time, after 50 years of watching state hospital bed numbers inexorably shrink, bed proponents fear that beds will continue to be closed until none are left. It is time to retire the extremes of both viewpoints. Three generations of pharmacological treatment development³ and federal laws and programs such as the Social Security Disability Insurance program, the Americans with Disabilities Act, the Children’s Health Insurance Program (CHIP) and its 2009 reauthorization, the Individuals with Disabilities Education Act (IDEA), and others now ensure that individuals with chronic conditions and disabilities, regardless of income, will be integrated into society and entitled to lives of inclusion.

At the same time, a recognition that hospital beds continue to play a vital role in providing acute and chronic care for a segment of the population with serious mental illness at times of need is widespread. This recognition has prompted some states and providers to reexamine bed numbers, and generated unprecedented support for repealing federal limits on Medicaid reimbursement to adult psychiatric facilities of more than 16 beds. Halting bed closures has been another approach.⁴ With the extremes laid to rest, we will be better prepared to discuss the full continuum of psychiatric care in all its aspects.

STATE HOSPITAL BEDS AT THEIR PEAK...

It is 1955. There are nearly 560,000 state hospital beds in the United States – 337 for every 100,000 men, women, and children.

The beds are occupied by patients with a wide variety of medical, neurological, and psychiatric conditions, including epilepsy, neurosyphilis, developmental and intellectual disabilities, schizophrenia, depression, and geriatric dementia, among others. Monuments to a 19th century period of social reform and a century of construction, many are sprawling clusters of buildings – the urban ones set in vast manicured lawns, the rural ones operated as self sustaining communities with their own farms and factories. In heavily populated areas like Southern California, it is nearly impossible to cross a county line without coming across a state hospital complex. Some patients stay briefly, while stabilizing from a mental health crisis; others enter in their youth and grow old on the state hospital grounds.

While the pendulum has continually swung between permissive and restrictive admission criteria, access has generally tilted toward allowing families to admit their young and adult children, spouses, and elderly parents to state institutions with little legal scrutiny, process, or question. Individuals may self admit as well. Patients are also committed by the courts because they meet civil commitment criteria that are typically broad and focused on a need for treatment, or because of simultaneous criminal justice involvement, a circumstance that ultimately becomes known as forensic or criminal justice involvement.

The quality and condition of the facilities and the treatment they provide is as varied as the patient population itself, some infamously decrepit and abusive, others therapeutic. Outside the hospitals, relatively few community centers have emerged to replicate, supplement or sustain the functions of the state hospitals.

All of this is about to change.

HOW WE GOT HERE

The period of state hospital downsizing and closure that has come to be known as deinstitutionalization began in the United States in the 1950s and, with a few exceptions, eventually became a worldwide phenomenon.^{5,6} Although federal legislation in the 1960s vastly accelerated the trend, deinstitutionalization grew from a confluence of political, social, legal, ideological, clinical, economic, and other forces that began to emerge two decades earlier.⁷

By the 1940s, physical deterioration of many state hospitals nearing the century mark and deplorable conditions inside them were prompting media exposés and congressional hearings. Returning World War II veterans with psychiatric injuries expected to receive care in their home communities, not in institutions.⁸ In 1953, the discovery of the antipsychotic effects of chlorpromazine (trade name Thorazine) made it possible to sufficiently resolve symptoms that individuals with psychotic disorders could, for the first time, live safely and stably in the community. On their own, a few states had begun recognizing the benefits of moving toward a decentralized, community-based model of care and opened community mental health centers. Already by 1955, state hospital bed numbers had peaked.

Fuel for the nascent shift came in the 1960s from the federal government. The Community Mental Health Centers Construction Act (CMHCA) of 1963 established community-based treatment as the national standard of care for people with mental illness and intellectual disabilities by authorizing construction of a national system of community mental health centers. Two years later, in 1965, the Social Security Disability Insurance program established Medicaid insurance for low-income individuals and those with mental health disabilities. By the early 1970s, lawsuits were restricting civil commitment. The ethos of society at the same time was shifting toward recognition of individual empowerment and autonomy. Due to these and the earlier developments, the pendulum swung away from the state hospital model and toward community-based care.

Had the community mental health centers envisioned by the CMHCA been developed to meet the needs of the full spectrum of psychiatric patients, including those with special needs, the system would likely have evolved differently. Instead, a succession of U.S. presidents and Congresses reduced and eventually eliminated federal funding for community-based mental health centers.

Meanwhile, Medicaid reimbursement was and has since been prohibited for treatment of individuals aged 22 to 64 hospitalized in psychiatric facilities of more than 16 beds, a provision known as “the institutions of mental disease (IMD) exclusion.” This economic disincentive efficiently motivated states to downsize or close existing state hospitals and discouraged private enterprise from developing alternatives of more than 16 beds. In 2014, NASMHPD’s *The Vital Role of State Psychiatric Hospitals* described this evolution of state hospitals. The report found that although some states had succeeded in building community-based systems or aspects of them, and peer-provided recovery services had begun to emerge, demand for mental health services had often outstripped community resources.⁹

For some populations, more tailored systems developed. Mental health services for children, for example, shifted to emphasize retention in family settings and brief placements rather than longer institutional care. For some conditions (e.g., neurosyphilis and epilepsy), medical discoveries produced cures or effective treatments for disorders that previously had been treated in state hospitals. For older adults, other long-term support services and models were crafted, and nursing homes took over the role that state mental health institutions had

held in the prior century. For individuals with intellectual disabilities, policies and institutions began to be separated organizationally and financially from mental health services to better serve the population.

For many individuals with serious mental illness, community settings and systems produced the positive results envisioned in the beginning with many people with mental illness living successfully in the community. However, other subgroups of state hospital patients became underserved or unserved and began to cycle in and out of acute care settings or migrate to jails, prisons, homeless shelters, and similar settings, a trend that has come to be known as “trans-institutionalization” or “cross-institutionalization.”

Other trends contributed to this effect. Policies that criminalized drug use significantly impacted people with co-occurring disorders, routing them to jails rather than treatment. Housing market forces, restrictions on funding for housing, and “not-in-my-backyard” attitudes toward neighborhood housing contributed, too. Legislation to restrict criteria for commitment made it harder to intervene with individuals who declined or did not seek treatment until they became a risk of harm to themselves or others, at which point they increasingly attracted law enforcement response.

The net effect is problems like the following, which are widely recognized as symptoms of these and other system failures, including the lack of a full continuum of accessible psychiatric care:

- ◆ Psychiatric boarding, in which children and adults presenting in EDs are held for days and even weeks awaiting an open community hospital bed
- ◆ ED “streeting,” in which ED patients are discharged without supports
- ◆ Forensic wait-listing, in which defendants spend weeks or even months in jails awaiting a state hospital bed

INTRODUCING “TAYLOR”

Taylor is 20 and diagnosed with schizoaffective disorder. He lives with his divorced mother in a tidy home not far from the suburban high school where he graduated two years ago. His story will be used throughout *Beyond Beds* to illustrate both the gaps and the opportunities in the continuum of psychiatric care.

It is midnight, and Taylor has just returned to his mother’s home after several hours of drinking in a local park with his “friends,” the personalities that his mother and other people claim do not exist but he knows are real. He knows he shouldn’t drink a bottle of vodka like this, but once he starts, it’s hard to stop. The house is quiet, his mother asleep or pretending to be, but he feels nervous and harassed. Sometimes his friends whisper commands him to do things in exchange for their friendship that get him in trouble with his mother, even the police, and they get mad when he does not obey. Tonight, they want to hear glass breaking, and the compulsion to satisfy them is haunting and troubling but feels too powerful to overcome.

Taylor paces the living room and tentatively runs his fingers over a pane of glass at the front window before backing away and going to the kitchen. Beside the sink, he opens the cabinet where his mother keeps the dishes. So many dishes! Plates, bowls, glasses of all sizes. He chooses a small glass, the kind they use for orange juice, looks around for a target, and then hurls it against the farthest wall. The shards have not finished scooting across the floor before he hurls the next one and then another.

Taylor benefited from an individualized education program (IEP) in high school and consistently received treatment, psychotherapy and educational support after his hospitalization for a suicide attempt while hearing voices. But his safety network fractured when he turned 18. The adult mental health system required a re-review of his eligibility for the community mental health services he received and the public benefits that helped pay for them, which produced a lapse in his support.

BEDS BEFORE ADULTHOOD

The child/adolescent mental health system is as complicated as the adult system but in different ways. A continuum of care is as important for youth as it is for adults, but the roles and influences of families, schools, child welfare systems and the juvenile justice system add different nuances and contexts.

In the child/adolescent service system, program goals relate to maximizing the tenure of youth at home and in school. To fulfill these goals, an array of interventions have been implemented, albeit inconsistently across and within the states. Interventions include mobile crisis intervention with in-home follow up supports, parent-peer support and coordinator/system supports, therapies and navigators to help the family. In the more robust continuums, pediatricians may have access to child psychiatrists, and clinical, residential and transitional systems work together through family centered, youth guided planning in a system that is sensitive to cultural differences.

We show Taylor receiving a full spectrum of child/adolescent benefits as a way of illustrating how a full continuum of care can work, not because it always does work better than the adult system.

Eventually, Taylor was assigned to a new clinic, but psychiatrists were in short supply, and it took three months for him to get an appointment there. In the interim, he stopped taking medication for the first time and had his first encounter with law enforcement when police were called because he refused to stop an aggressive rant at a neighbor he believed was plotting to kidnap him. He eventually returned to the mental health clinic, but it was not particularly specialized in working with emerging adults. Taylor's adherence to medication and his engagement with treatment never returned to the consistency he achieved while in the children's behavioral health system.

Taylor's story is fictional but contains many common elements of serious mental illness and its treatment in the service delivery system: onset of symptoms in adolescence, disruptive hand-offs between service providers and at specific age cutoffs, irregular adherence to medication and other treatment in adulthood, worsened symptoms when not treated, behaviors that frighten others even when not intended to be dangerous, and suicidal thinking and behavior. From here through the conclusion of this assessment, he will be the human face illustrating where gaps in the psychiatric care continuum persist and where strategies for addressing them exist beyond merely building more beds.

In her bedroom, where she rarely sleeps when her son is out at night, Taylor's mother is jolted upright by the sound of shattering glass. For one merciful moment, she hopes the sound merely signals an accident in the kitchen; with the next crash, she feels sick with fear and dread. Taylor has never hurt her, and his mother firmly believes he never will, but as one glass after another hits the wall on the other side of her wall, she takes comfort in the dead bolt she has reluctantly installed on her door.

Groping for her cell phone in the dark, she wishes, not for the first time, that these episodes occurred only during business hours on weekdays. Then, she could have tried to reach Taylor's caseworker. Instead, finding the phone, she presses 9-1-1, desperately hoping tonight is one of the nights when an officer with mental health crisis training is on duty.

Early in the course of his illness, Taylor probably would have benefited from a specialized first-episode psychosis (FEP) program¹⁰ where evidence-based practices are provided as a comprehensive clinical strategy, but FEP programs did not exist when he first became symptomatic. In 2017, after nearly a decade of federal initiatives to expand such programs, they are growing in number, but most adolescents and young adults still live without access to one.

"Where is your son now, Mrs. Wilson? Can you still hear him?"

The police dispatcher does not hang up until officers have taken control on the scene. To Taylor's mother, the voice is a lifeline.

"I think he's throwing something bigger now, maybe cups. The sound is louder when they hit the wall."

"Officers should be there within two minutes. Do you have a safe path to a door to let them in?"

"I am locked in my bedroom. He probably left the front door open when he came in. The officers should be able to walk right in."

MENTAL ILLNESS IN THE CRIMINAL JUSTICE SYSTEM

Mental illness is global, but mental illness response is local, and whether a 911 call is made during a first psychotic break or a relapse, it triggers one of several response types reflective of the circumstances and local conditions. These circumstances include:

- ◆ the individual's behavior at the time;
- ◆ the state where the person lives and its laws, policies, and practices related to who can be held for psychiatric evaluation and where they may go for one;
- ◆ the robustness of the community's mental health services and their accessibility;
- ◆ the existence of emergency, crisis stabilization, inpatient, and recovery beds and personnel;
- ◆ the training of local law enforcement in de-escalation tactics;
- ◆ access to crisis stabilization centers and police drop-off sites;
- ◆ the availability of jail diversion programs for individuals with mental illness;
- ◆ insurance status;
- ◆ —and many others.

A crisis like Taylor's will usually mobilize one of the types of responses described in Figure 2.

The sequential intercept model is a framework based on the premise that criminal justice involvement of individuals with mental illness can be reduced by identifying and redirecting them into treatment at various intercept points along the criminal justice continuum (e.g., during police encounters and court proceedings, upon jail or prison entry or reentry, while on community probation or parole supervision).¹³ This framework, which was incorporated in the 21st Century Cures Act, has led to the development of many innovative diversion strategies as a means of reducing the likelihood that individuals with conditions like Taylor's will end up charged with a crime or in law enforcement custody.¹⁴ That many individuals at risk of criminal involvement also have substance use challenges is widely recognized.

CRIMINAL AND JUVENILE JUSTICE DIVERSION

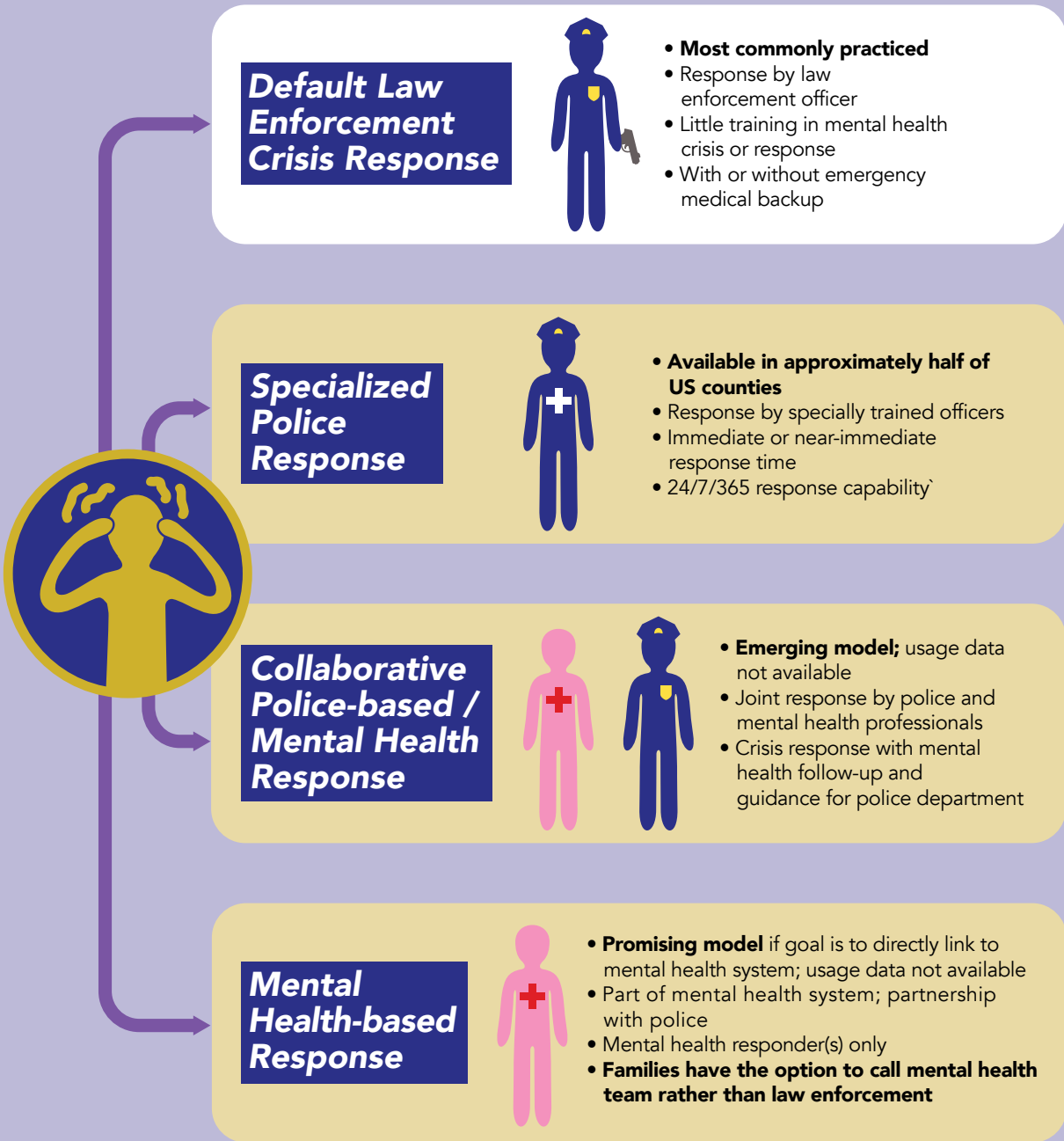
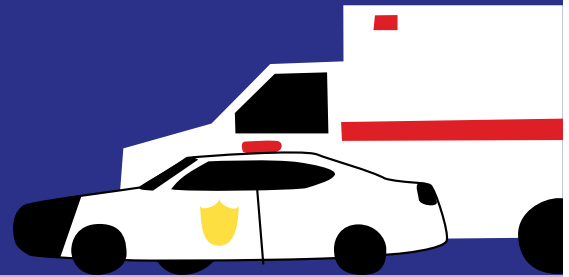
Though individuals with serious mental illness make up an estimated 4% of the population, "severe psychological distress" is reported to affect 26% of jail inmates and 14% of prison inmates overall and 20–33% of women inmates. Similar overrepresentation is seen in the juvenile justice system.

Evidence-based practices have been developed to prevent or diminish the prevalence of serious mental illness in the criminal and juvenile justice systems, but they are not universally available and remain underused.

RECOMMENDATION: Policymakers should fund and foster evidence-based programs to divert adults and youth with serious mental illness or emotional disorders from justice settings to the treatment system. These programs should operate at all intercept points across the sequential intercept framework and be required to function in collaboration with correctional and other systems.

Because his mother did not have the option of calling for a mobile mental health crisis response, Taylor's crisis has become a police incident, delivering him to this new "intercept" crossroads. Acting on the basis of their training and experience, the laws of their state, and practical realities such as the availability of acute-care options within their jurisdiction and how Taylor behaves on the scene, responding officers will decide whether Taylor's actions warrant his arrest on criminal charges, his transport to an emergency medical facility or their departure without further action. During the encounter, Taylor's risk of injury or death will be 16 times greater than that of members of the public without serious mental illness¹⁵ and his risk of arrest six times greater.¹⁶

EXAMPLES OF PSYCHIATRIC CRISIS RESPONSE



Taylor's episode occurs on a Friday night. If he is arrested and his mother is too fearful to post bail for his release, Taylor will be kept in jail custody over the weekend, without access to prescribed medication or other mental health supports, waiting to go to court. He will be at risk of victimization,¹⁷ suicide¹⁸ and other violence.¹⁹ If symptoms of the psychiatric state that led him to the dish-smashing episode are still evident when he reaches the courtroom (e.g., Taylor appears confused/disorganized/aggressive, makes statements that seem out of touch with reality, does not understand why he is before a judge or cannot communicate with his counsel), the judge may order an evaluation of Taylor's competence to stand trial before the matter can move forward in the criminal justice system.

Although practices vary by state, criminal competency evaluations typically take place in the jail, in the community or, less commonly, at the courthouse or state hospital. Once an individual is adjudicated incompetent to stand trial, laws in almost all states require restoration to legal competence before trial. Most states provide such restoration services in their state hospitals²⁰ even when the services are legally authorized for other settings, such as the community.²¹ These services include medications and individual and classroom therapies but also explicitly teach information about courts and criminal processes.

When the number of pretrial jail detainees court-ordered into the state hospital for competency services exceeds available beds, forensic waits develop. These waits average from weeks in some states to more than a year in others,²² and their numbers have been growing.²³ State mental health directors report that court-ordered restoration services are the single greatest source of pressure on state hospital bed supplies. States are attempting to reduce or eliminate their bed waits, but waitlists remain common, and many states have been sued—sometimes repeatedly—or threatened with lawsuits over the situation.²⁴ Some innovations hold promise for reducing forensic bed waits. Miami-Dade County in Florida has implemented a successful strategy for reducing bed waits by diverting individuals with psychiatric symptoms who commit minor criminal offenses directly to crisis stabilization units in the community instead of booking them into the county jail,²⁵ for example, and computer modeling is being explored as a tool for identifying small changes in common practices that would reduce forensic bed waits without adding beds.²⁶

Family caregivers of individuals in crisis often call police under the assumption that law enforcement involvement will ensure their loved ones' safety and get them into treatment. Police say they arrest individuals in crisis for the same reasons and for public safety, and judges say they order competency restoration because there are no other accessible treatment options.²⁷ However, restoring criminal competence to stand trial is fundamentally a process to ensure that criminal defendants can participate in their own defense. Confinement and security, not treatment, are the priorities in correctional systems, and recent government data indicate that only one in five jails provides any form of psychiatric treatment to inmates.²⁸ Some pretrial defendants spend far more time waiting for competency services or undergoing them than they would have spent if convicted of their alleged offenses. Others are restored and returned to jail, where they relapse, return to the hospital, and cycle through the process anew, trapped in a revolving door of personal suffering and public cost.

A continuum of care that promotes mental health stability before law enforcement encounters occur and diverts individuals with mental illness from jail if they do occur (e.g., through mental health training for law enforcement, mental health specialty courts, or forensic assertive community treatment [ACT] teams) reduces the risk of arrest. However, such interventions and strategies are not sufficiently widespread and accessible, and thus the demand for competency restoration in state hospitals continues to grow.

MENTAL ILLNESS IN THE EMERGENCY DEPARTMENT

Despite the circumstances, Taylor is lucky. The officers who respond to his mother's 911 call are experienced in crisis intervention. They even know Taylor, having been called to the family home in previous emergencies. Though they are aware that calls involving psychiatric symptoms can be volatile, the officers act relaxed and friendly, asking him, "What's happening, man?" and giving him ample time and space to respond. They suggest that getting some sleep and a checkup at the local hospital might help him feel better.

Taylor stands, silent, arms slack at his sides, staring at his mother's door for several minutes. "Mom!" he finally shouts. "These guys want me to go to Community General with them."

The lock clicks open and his mother steps into the room. Taking in the broken glass and ceramics on the kitchen floor, she says, "Oh, Taylor. It's such a mess here, and it's already so late. Why don't you go with the officers? I'll come along and keep you company until they get you into bed."

Taylor squeezes his eyes shut, gives an exaggerated shoulder roll. Finally, with a sigh, he mutters, "Okay. Just for one night."

When there is an incomplete continuum of care, law enforcement and families rely on the Emergency Departments (EDs) of their local hospitals for psychiatric crisis intervention. The demand this creates contributes to ED crowding and often results in psychiatric "boarding," a practice in which psychiatric patients whose condition merits hospital admission are held in the ED because no inpatient bed is available to admit them.

The American College of Emergency Physicians (ACEP) reports that 90% of hospital EDs board psychiatric patients,²⁹ with bed wait times averaging three times what non-psychiatric patients experience.³⁰ Bed waits in EDs can last days or even weeks, and lawsuits, court orders, and costly settlements have resulted, just as they have with jail waits.³¹ Studies of boarding patterns indicate that psychiatric patients who have the most extreme symptoms or are the most suicidal often wait the longest for admission or are discharged without care because of the difficulty of matching them to beds.³² Virginia State Senator Creigh Deeds tragically became the face of this phenomenon when his son, Gus, stabbed and slashed him in the head and then killed himself hours after being released from an ED because personnel said they could not find a bed for him within Virginia's statutory time limit for admission.³³

ACEP for two decades has been proposing strategies to reduce ED crowding, but reports only "minor gains" from the efforts.³⁴ The intractability of the problem despite efforts by this and other organizations and agencies reflects its complexity. Boarding is a symptom of need and resources that are not balanced. These needs include

- ◆ patient access to preventative and access to supports in the community that reduce the likelihood of crisis (e.g., ACT teams);³⁵
- ◆ hospital access to real-time information about where and what kinds of beds are available (e.g., state bed registries);
- ◆ availability of intensive-care treatment alternatives outside of hospitals (e.g., crisis stabilization units in the community);

- ◆ law enforcement training and practices that influence whether law enforcement encounters like Taylor's are de-escalated at the scene (e.g., crisis intervention training)
- ◆ governing state laws and criteria that influence the volume of involuntary mental health evaluations and hospital admissions initiated through EDs;
- ◆ the absolute number of beds available within the hospital or within transport distance;
- ◆ the licensing and distribution of those beds (e.g., by gender, age, purpose); and
- ◆ staffing resources, including sufficient numbers of qualified mental health professionals willing to treat the population whether patients are in the public or private sector.

Changes in practice at any point on the continuum of care connected to the ED can impact boarding dramatically. One 2017 study, based on computer modeling, found that adding a single half-time clinician during the 8 a.m. to 4 p.m. shift could cut average wait time to discharge by 35% and average wait time to admission by 13%.³⁶ Conversely, when Sacramento, California, closed an outpatient crisis stabilization unit and eliminated 50 of 100 inpatient beds in 2009, the number of ED visits requiring psychiatric consultation at the city's university hospital tripled, and the average time psychiatric patients spent waiting to be seen by a psychiatric clinician in the ED increased from an average of 14 hours to nearly 22 hours.³⁷

Relevant to treatment systems across the continuum, studies and surveys consistently find that patients in psychiatric crisis do not receive the same quality of health care in the ED that patients presenting with other medical conditions receive. Provider biases and prejudices that result in inferior intervention are reported.^{38, 39} Misinterpretations and over-interpretations of confidentiality provisions of the Health Insurance Portability and Accountability Act (HIPAA) in psychiatric cases often leave caregivers out of treatment discussions that family members of other medical patients are afforded.⁴⁰

EDs under-equipped to handle mental health emergencies may be even less prepared to expeditiously evaluate and place patients with co-morbid conditions such as substance use, intellectual/developmental disabilities including autism, sensory issues including deafness, and others.⁴¹ "Emergency in the emergency room" is how more than a few observers have described the situation.

As he would in most EDs in the United States, Taylor finds himself waiting in the general ED population to be evaluated. Next to the broken-leg patient in the wheelchair and not far from the stabbing victim with a blood-soaked T-shirt wrapped around his wounds, Taylor grows increasingly anxious. The lights, bustle, and sounds add to the sensory overload he is already experiencing from his psychotic symptoms. He begins rocking in his chair, his lips moving as he talks softly to the voices in his head, his fingers repeatedly rising to the shirt pocket where his cigarettes usually rest, then dropping as he finds it empty. When he jumps to his feet and begins gesticulating in his inner conversation, surrounding patients begin to look alarmed. The stabbing victim's girlfriend sidles away to find a nurse.

Taylor's mother wavers between staying next to her son and leaving to plead the case for finding a cubicle for him or at least a calmer corner. She feels guilty for promising him the hospital would be quieter than home. It never is.

EMERGENCY TREATMENT PRACTICES

The Emergency Medical Treatment and Labor Act (EMTALA) is a federal law that requires stabilization and treatment of all persons coming to an ED prior to transfer, regardless of their insurance status or ability to pay. Nonetheless, psychiatric patients wait longer in EDs than other medical patients for admission and experience other disparities, including discharge without treatment or even arrest. Potential receiving hospitals are not obligated to accept patients from EDs.

RECOMMENDATION: *Federal, state and local agencies should monitor hospitals for adherence to EMTALA in their EDs and levy sanctions for its violation, including the withholding of public funding. Hospitals with licensed psychiatric beds that refuse referred patients should similarly be sanctioned if monitoring shows they have a record of refusing referred patients without legitimate cause.*

Each year, there are an estimated 800,000 ED visits in the United States where the cause is symptoms of schizophrenia and 1.5 million visits where the presenting problem is associated with a mood disorder.⁴² Optimally, psychiatric patients are seen in an area of the ED where they can be evaluated and cleared medically, then examined by a mental health specialist in no more time than a stroke or sepsis patient would wait for comparable services. At a minimum, a private space to distance them from the tumult of the ED, which can intensify symptoms is available, an accommodation that is especially critical for individuals who might find the sounds and activity of the typical ED overwhelming. In practice, most psychiatric patients are seen in the general ED, where, like Taylor, they are given a seat or a gurney and may spend hours or days in a public hallway.

An ED visit is another crossroads. What transpires there determines the patient's next step along the continuum of care, or off it. Figure 3 displays the most common ED outcomes for psychiatric patients.

The outcome that any individual patient experiences, like arrival at the ED itself, is a function of multiple factors, including the gravity of the symptoms; the patient's behavior; the availability of appropriate beds; the clinical assessment of the evaluator; the tenacity of the patient's advocates, who may include family members, outpatient providers and caretakers; and transient factors such as whether the hospital has a psychiatrist on staff.

All other factors being equal, however, if the supply of appropriate beds does not match the demand for them at this juncture, hospital admission likely will be delayed or denied altogether.



Discharge by Arrest

- **Departure from the ED in police custody**
- Perceived as relatively uncommon
- Used when patient's behavior escalates beyond ED's capacity



Discharge Without Support

- **Also known as "streeting"**
- Perceived as relatively uncommon
- Discharged to the community without outpatient support



Discharge With Support

- **Symptoms have abated; return to community is reasonable and safe**
- Appropriate follow-up and outpatient support have been secured

1 in 5 ED patients with schizophrenia or mood disorders were discharged with support in 2015



Boarding

- **Bed waits of days, weeks or months in the ED**
- No appropriate placement is available

29 of 46 Responding states reported ED boarding in 2015
90% of ED physicians report boarding psychiatric patients



Hospital Admission

- **Admission to same hospital or elsewhere in the community**

38% of psychiatric ED patients admitted to the same hospital in 2015

Patients admitted to short-term-beds in another community hospital **8%**

5.8% Patients admitted to non-psychiatric "scatter" beds

EMERGENCY DEPARTMENT OUTCOMES

PSYCHIATRIC HOSPITALIZATION

It is nearly 7 a.m. Taylor has been evaluated and determined to need hospitalization for monitoring and stabilization. Once she was assured he would have a bed, his mother went home to get some sleep. Taylor has been moved to a gurney pushed into a quieter corner of the ED, where he waits. He rejected the food his nurse brought him and is drowsy after accepting medication to relieve his anxiety.

There are no beds open in Community General's psychiatric unit. Under a contract with the county, the private hospital accepts patients held involuntarily as a danger to themselves or others, which makes voluntary patients like Taylor a lower priority for admission. There is no real-time bed registry for acute hospitals in his state. This leaves the crisis triage worker to hunch over a telephone in a cubicle off the nursing station, making call after call, hunting for a placement, a routine she follows several times in a single shift.

Most hospitals report that they are full or their units are currently too active, and maybe it will be better in the morning. A hospital two hours distant from Community General confirms it can admit Taylor. It takes another hour for the ambulance to arrive to transport him and two hours for the drive. It will be hours more before his mother finds him because Taylor left home without his cell phone and, observing confidentiality protections, Community General will not tell her where her son is or even confirm that he has been discharged to a hospital and not to the streets.

Even so, Taylor is again fortunate: His wait to admission lasted less than half a day. The nurse in the psychiatric unit when he arrives is welcoming and tells him it is fine to sleep through the morning group therapy session because he has earned some peace and quiet.

Inpatient treatment remains a vital component of the continuum of care.^{49,50,51,52} At a minimum, emergency hospitalization allows time for stabilization of acute psychiatric symptoms, much as intensive care in a cardiac bed promotes stabilization of acute cardiac symptoms. When state hospitals functioned as virtually the entire mental health system, they were the

PSYCHIATRIC BEDS

A full continuum of care includes a sufficient number of beds to meet the acute, intermediate and long-term needs of those individuals with mental illness who require more intense or specialized services than are available in the community. Currently, statutory, licensing, funding and other policies are combining to limit bed supply and access in most states. Hospitals receiving public funding are not required to have psychiatric beds to serve their communities, and patients are often then hospitalized at sites far away from home.

RECOMMENDATION: *Identify those policies and practices that operate as disincentives to providing acute inpatient and other beds or that act as obstacles to psychiatric patients accessing existing beds (e.g., the IMD exclusion) and require hospitals benefiting from taxpayer dollar investments to directly provide or ensure timely access to inpatient psychiatric beds.*

main disposition point for patients transferred from community hospital EDs, whether voluntarily or involuntarily. It is largely a result of this model that state hospitals continue to be viewed as synonymous with psychiatric hospitalization.

Today, however, inpatient care extends far beyond state hospitals and far beyond hospitalization in other settings as well. Psychiatric hospitalization itself has been transformed. In 2014, approximately 75% of residential psychiatric beds were located outside of state and county hospitals,⁵³ and fewer than 2% of all public mental health care clients were treated in state hospitals.⁵⁴ Individuals 65 years of age or older, who made up 29% of the state and county hospital population in 1970, were being largely cared for in the community.⁵⁵ Although some state hospitals continue to accept voluntary patients, the majority of state and county beds are reserved for civil patients deemed by a court to meet criteria established by each state for involuntary commitment or, increasingly, by forensic patients involuntarily committed through the criminal justice system.^{56,57}

In the hospital, Taylor is seen every day by a psychiatrist on rounds and goes to group therapy sessions led by an occupational therapist. The groups are mixed, some interesting and some not. He spends time in the day room, which is better than some he has seen, with a foosball game and a game table. In therapy with his social worker, he fills out familiar lists about "triggers" that upset him, his goals, and where he sees himself in a year. Already, she is talking to him about discharge.

Taylor's social worker asks him about the medications he has been on over the years and what he likes and does not like about them. He says he noticed that he mostly stays out of trouble when taking medication and makes plans for getting a job, saving up money for his own car, and having a girlfriend. What he does not like is that the medications make him gain weight, but do not make the voices stop ordering him to do things he probably should avoid, like breaking his mom's dishes.

Various members of his team describe a drug the doctor discussed with him at a treatment team meeting called clozapine. The nurses tell him people who have a history of drugs that do not eliminate symptoms often find this one works for them. They call that one of the pros. There are cons, too: regular blood testing, drooling at night and, probably, continued struggles to keep his weight down. His social worker asks him to consider going on clozapine despite the cons because it could control his symptoms better and make it easier to follow through on his plans and dreams. He says he will consider it.

As with other medical conditions, insurers require clinical evidence that a continued hospital level of care is necessary at this point. With psychiatric hospitalization, justification requires describing impairments resulting from continued symptoms that cannot safely be managed without around-the-clock medical monitoring. Taylor's hospital experience illustrates how this strategy works in practice. On his third day of intensive hospital treatment, Taylor agrees to give clozapine a try. By then, he has accepted anti-anxiety medications and a few doses of antipsychotic medications when he complained the voices were overwhelming him. He is noticeably calmer and more focused in groups and is interacting socially with other patients. This all goes into his medical chart. He is still distracted by voices others cannot hear, but he opens up to his social worker, has no behavior issues, and reports and demonstrates no intention to harm himself or others. On the fifth day, his psychiatrist documents in Taylor's

DATA DRIVEN SOLUTIONS

Evidence-based public policy and practice require reliable, comparable, scalable data from which to identify, quantify, and analyze individual and community outcomes and thus implement best practices. Under new federal direction, more such data are becoming available, but their value to policymakers and the public continues to be limited by the lack of common definitions and methodologies, by delays in publication, and by barriers to public access.

RECOMMENDATION: *Policymakers should prioritize and fully fund the collection and timely publication of all relevant data on the role and intersystem impacts of severe mental illness and best practices.*

clinical notes that he is ready for a step-down placement. The insurer lowers payment to the hospital based on this finding, and the hospital's actual costs are no longer fully covered. Discharge becomes imminent.

In 2014, the federal government reported 800,000 hospital discharges of patients with schizophrenia and 1.5 million discharges of those with mood disorders, including bipolar disorder and major depression. Discharge practices vary by state and by county within states and are influenced by state laws, public policy priorities, state and local budgets and a host of other factors. While two to three weeks are necessary for antipsychotic medications such as clozapine to reach a therapeutic level at which they significantly reduce symptoms, few patients outside of state hospitals remain inpatients long enough for that to happen. In 1980, the median length of stay (LOS) for an acute episode was 42 days.⁵⁸ By 2014, it was about seven days.⁵⁹ At 77 days, the average LOS is much longer in state hospitals,⁶⁰ one of the reasons that some researchers, advocacy groups, family members and others continue to call for more state hospital beds.

One analysis compared state data and found shorter state hospital LOS to be associated with higher rates of readmission,⁶¹ but the link between LOS and outcomes is largely unexplored at the patient level. Those data that do exist about LOS typically are not diagnosis-specific, making it difficult to determine whether LOS is more critical for some diagnoses or symptoms than others. This dearth of information deprives all the stakeholders of an essential ingredient for evidence-based LOS guidelines and practices. Also lost are the findings necessary to make an outcome- or cost-based rationale for expanding transitional residential beds as a means of reducing the demand for hospital beds and improving mental health outcomes overall.

In a more complete continuum of care, Taylor's episode likely would have been avoided entirely, or he would have gained immediate access to the level of care needed, avoiding the encounter with police, visit to the ED, and hospitalization. The next stage of his journey illustrates how an integrated approach with a full spectrum of appropriate services works to achieve better outcomes.

TRANSITIONAL BEDS

Taylor's social worker is the one who tells him about Stepping Stones House. He will eat and sleep there temporarily, but it is not a hospital, she promises. It is small – only six beds in a real house, in his home county. He will see some of the same kinds of people he does in the hospital – a social worker, a psychiatrist, a caseworker – but he will meet new ones. Stepping Stones' staff will introduce him to an entire team that will be "his" once he moves back to his mother's home or to another setting. They will link him to the clozapine clinic that operates at an academic medical center he will be able to reach by public transit. While his medications are still being adjusted and his psychiatric symptoms continue to subside, Stepping Stones will work with Taylor to map his next steps and provide the linkages to services that will support his further recovery.

Taylor also will be connected with a young adult peer with a serious mental illness diagnosis who has been trained to support others with similar disorders and help them navigate their own recovery journeys. As long as Taylor attends group sessions and stays on the plan his treatment team has developed with him, he will be able to go on unsupervised outings with his mother or the trained peer. And after two weeks, maybe less, he will move to an even less restrictive setting that his team inside and outside Stepping Stones will work with him to select. His mother says he is welcome to come back home, but the Stepping Stones House staff also can introduce him to group living options near his home if he wants to try something different until he is ready to live more independently.

LINKAGES

Outpatient supports could effectively increase bed capacity by reducing the number of patients in need of inpatient care. However, because these often are unevenly distributed and operate in silos rather than in collaboration, system inefficiencies occur that create barriers to recovery as individuals are left to themselves to navigate a complex array of interventions despite their significant mental health and other challenges.

RECOMMENDATION: Policymakers should recognize that mental health, community, justice and public service systems are interconnected and adopt and refine policies to identify and close gaps between them. Practices should include providing "warm hand-offs" and other necessary supports to help individuals navigate between the systems in which they are engaged.

Residential treatment beds are the fastest-growing category of capacity in the United States. Since 1970, the number of such beds has doubled, from 6.8 beds per 100,000 people to 13.5 per 100,000 in 2014.⁶² Terminology differs by locale. They may be described as "respite," "transition" or "step-down" services, or by another name, but their essential characteristic is providing a place to stay that is monitored by non-medical staff who are trained in medication administration and who provide transportation and other support and structure. They generally do not have a psychiatrist or a nurse on-site but may have medical personnel on call in the case of an emergency. The stays are short-term, typically four weeks or less.

Functionally, transitional beds may operate either as a hospital diversion or a hospital step-down strategy. Residents typically are referred by the public mental health system, hospitals

or other public agencies; individuals and private providers cannot access them. Had Taylor still been engaged with the mental health system when symptoms that led to his latest psychotic episode began, he could have been referred to Stepping Stones to head off the emergency. Respite, structure, abstention from alcohol and other substances, refocusing on his goals, medication adjustments, and other supports might have stabilized him sufficiently to return home and carry on with no further intervention. The police call, ED visit, and hospital stay would have been averted, along with the resulting stress on Taylor and his mother and the costs to the systems involved. Had he continued to destabilize, he could have been transferred from Stepping Stones to the inpatient unit, and perhaps back again before returning home.

TECHNOLOGY

Mental health applications for computer and other technologies are proliferating and hold promise for promoting more precise, timely and effective treatment for individuals with serious mental illness. At the same time, computer models are emerging that equip decision makers to analyze large data sets and project the impact of small changes to systems of care to better tailor interventions toward positive outcomes. Technology assisted medical record keeping has increasingly been constructed to preserve and draw down clinical information, while maximizing allowable sharing of such information between clinicians through health information exchanges.

RECOMMENDATION: *Policymakers should create and expand programs that incentivize and reward the use of technology to advance care delivery, promote appropriate information sharing and maximize continuity of care. Policymakers should require as a condition of such incentives that outcome data be utilized to help identify the most effective technologies, and they should actively incorporate proven technologies and computer modeling in public policy and practice.*

There have been few studies to assess the effectiveness of transitional residential programs in producing measurably improved outcomes, but their role in linking people with mental illness to evidence-based programs and other promising supports strongly suggests an indirect association. For example, Stepping Stones staff makes sure every qualifying resident moves on with an active application for services such as mobile ACT teams, and members of the ACT team for his area will come to Stepping Stones to meet Taylor. Sometimes called “hospitals without walls,” the ACT model has repeatedly been found to reduce re-hospitalization and improve other outcomes.

Because of the nation’s psychiatrist shortage, Taylor may have to wait a month or two for an appointment with a supervising psychiatrist, as he did when he transitioned from youth to adult services. To bridge that gap, the staff at Stepping Stones introduces Taylor to a tele-psychiatrist from a different region

who is on contract to provide interim services. Taylor also is introduced to some of the newest mobile apps for mental health. Although still to be fully studied, apps show promise in monitoring symptoms and keeping patients connected to their community providers.⁶³ He is allowed to use his mobile phone for an extra hour each day if he downloads at least two apps and works at becoming familiar with them. Interestingly, Stepping Stones staff also are encouraged to use apps to manage their own stress and mitigate compassion fatigue.

Stepping Stones is able to bill Medicaid for Taylor’s medication supervision and some of its services, but the rest of its services are funded by Taylor’s county. By tracking and analyzing intersystem costs, the county was able to determine that funding Stepping Stones 24/7, 365 days a year costs less than maintaining the status quo without hospital diversion and hospital step-down.

WORKFORCE

The capacity of any system to deliver services effectively and efficiently is impaired by workforce shortages. Both outpatient and inpatient mental health services and supports are being limited in many locations because there are not sufficient numbers of trained workers and certified peers to provide them. These neglected services include psychiatric beds that cannot be used because they are unstaffed. Limiting services in turn limits opportunities for recovery and the benefits of recovery to individuals and their communities.

RECOMMENDATION: *Policymakers at every level should initiate assessments to identify, establish and implement public policies and public-private partnerships that will reduce structural obstacles to people entering or staying in the mental health workforce. This workforce includes peer support for adults and parent partners for youth and their families. These assessments should include, but not be limited to, educational and training opportunities, pay disparities, and workplace safety issues, and the assessments should be conducted for the workforce across all positions.*

For example, county officials found that law enforcement officers had spent more than 60,000 hours during the previous year driving people in psychiatric crisis to EDs, between EDs and admitting hospitals, and more rarely, to the state hospital, four hours away. The county's costs for psychiatric emergencies also included paramedic hours, ED, and local hospital charges for patients held for emergency evaluation, the costs of medication for inmates in the county jail, and medical costs for citizens and law enforcement injured during encounters.

A majority of the county commissioners eventually decided that every county resident with a serious mental illness who did not have a crisis in any given year represented a dollar—or many dollars—saved. By the time Taylor entered Stepping Stone House, the county mental health department had already been directed to find another small residential house where a second Stepping Stone House could be opened.

LIVING IN THE COMMUNITY

Taylor leaves Stepping Stones after three weeks. He goes back to his mother's home for the time being, but he is on a waiting list for a room in a staff-supported group living environment not far from where she lives. He has mixed feelings about leaving his boyhood home because there he knows what to expect, and his mom's food is good. But most of the friends with whom he went to high school went away to college after graduating. For now, this is a step in a similar and hopeful direction.

PARTNERSHIPS

A growing number of advocacy organizations, faith based communities and others outside the mental health field are emerging as able and willing to support and supplement public resources. In some circumstances, such as with children, families are being included in treatment and policy development in new and more vigorous ways.

RECOMMENDATION: *Policymakers should recognize the vital role that families and non-traditional partners outside the mental health system can play in improving mental health outcomes and should encourage and support the inclusion of a broader range of invited stakeholders around mental illness policy and practice.*

Taylor's trajectory is unlikely to be without further setbacks. He lives with a serious mental illness that can be unpredictable, with symptoms that come and go and can be more or less impairing at different times. He will be more stable and successful while consistent with medications, but there can be breakthrough symptoms or incomplete remission and, like most people with chronic conditions, it is likely he will periodically go off his prescribed medicine.

Depending on the symptoms he develops when he rejects treatment, civil or criminal courts may become involved in his care. He will have a range of side effects from annoying to, in very rare cases with clozapine, life-threatening. The weight gain associated with his medications places him at risk for developing comorbid health conditions, such as diabetes. His cigarette smoking compounds his risks.

Taylor's trajectory will, to some extent, depend on how thoroughly and successfully his local mental health agency is funded and how it is equipped to invest in programs that promote his well-being and success. He will benefit from access to integrated health care in which his medical and mental health providers collaborate on his treatment and care. His mother will remain a critical foundation of his sta-

bility, as family members can be, but she will need support and encouragement, too. Ultimately, Taylor's recovery will be a product of how completely the continuum of care serves him, along with his own courage and determination.

When he leaves Stepping Stones House after a stay of nearly three weeks, Taylor feels more hopeful than he has in a long time. His team has expanded well beyond his mom and a caseworker. He moves into a house with a half-dozen other young men and women with disabilities and enters a Clubhouse International day program nearby. There, he meets and socializes with others in mental health recovery and receives employment coaching. Through the Clubhouse's introductions, he gets hired as a bagger by a local grocery store committed to employing people with special challenges. Clubhouse emphasizes and encourages sobriety to participate, which motivates Taylor to follow through with a vow to stay away from substances that have undermined his recovery in the past. After one of his new friends introduces him to a local church program that provides scholarships to attend

the local community college, he enrolls in a psychology class. On his first night back in school, he meets a young woman who eventually becomes his girlfriend.

Taylor has one short relapse after he decides he has recovered beyond any need for medication and stops taking his clozapine, but he stabilizes quickly during a brief stay at Stepping Stones and returns to his group living environment, job, and girlfriend. Occasionally, the old voices break through and speak up again, but he has learned tactics for ignoring them, and he no longer gets into trouble when they do. As he works his way to the top of the list for a supported housing apartment, he and his case manager agree he is ready for less frequent appointments, and his meetings with the peer support worker from Stepping Stones shift from weekly to twice-monthly.

Taylor is on his way.

CONCLUSION

Taylor’s story, although fictional, represents the challenges of a young adult with a chronic and serious mental illness. His role in this paper is to illustrate both the gaps and the opportunities in the continuum of mental health care. We depict him as having received excellent supports as a young adolescent with youth-guided and family-driven care, and then, when our story begins, experiencing symptoms and personal setbacks after the transition to adult services.

Comparatively, his narrative illustrates more positive than negative outcomes: He was not arrested during his crisis, spent less than a day in the ED, was admitted to a psychiatric bed for treatment of his acute symptoms, accepted new medication, and was discharged to transitional care, which became a turning point. “More positive than negative,” however, should not be considered acceptable for someone like Taylor, but more psychiatric beds alone would not have improved the outcome.

A robust system of care for individuals with serious mental illness must look beyond beds and offer comprehensive and quality treatment and services before, during, and after acute illness episodes. Without a broader view of what is needed, individuals with mental illness will remain at risk of negative outcomes, including hospitalization and rehospitalization, arrest and re-arrest, homelessness, and even early death. Efforts across the country are underway to build successful alternatives to these outcomes—a good start—but validation, replication, and proliferation of effective treatment practices for individuals of all ages are urgently needed in communities of every size nationwide.

The era of mental health care that is centralized and provided primarily through government-operated inpatient facilities is over. For more people with serious mental illness to survive and thrive, we need better early detection and prevention practices, more precise diagnostic methods, more targeted and effective medications with fewer side effects, more parity with care for other medical conditions, and less isolation for individuals with psychiatric illness. We need to know more about why devastating co-occurring substance use is so common in mental illness and develop effective approaches to reducing it.

On every level, the rush to “more beds” needs to be tempered with illumination and clarity about patient need, the kinds of beds best suited to meet those needs, and the recognition that bed capacity is a function of more than sheets on a mattress. Only a complete continuum of psychiatric care can reduce the human and economic costs associated with mental illness.

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The Treatment Advocacy Center is a national nonprofit organization dedicated exclusively to eliminating barriers to the timely and effective treatment of severe mental illness. The organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of innovative treatments for and research into the causes of severe and persistent psychiatric illnesses, such as schizophrenia and bipolar disorder.



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The National Association of State Mental Health Program Directors (NASMHPD) represents the state executives responsible for the \$41 billion public mental health service delivery system serving 7.5 million people annually in all 50 states, 4 territories, and the District of Columbia.



Community Crisis Response

Rapid Improvement Event 2: *Testing and Developing Solutions*

Mental Health Discussion: May 5, 2021





AIM:

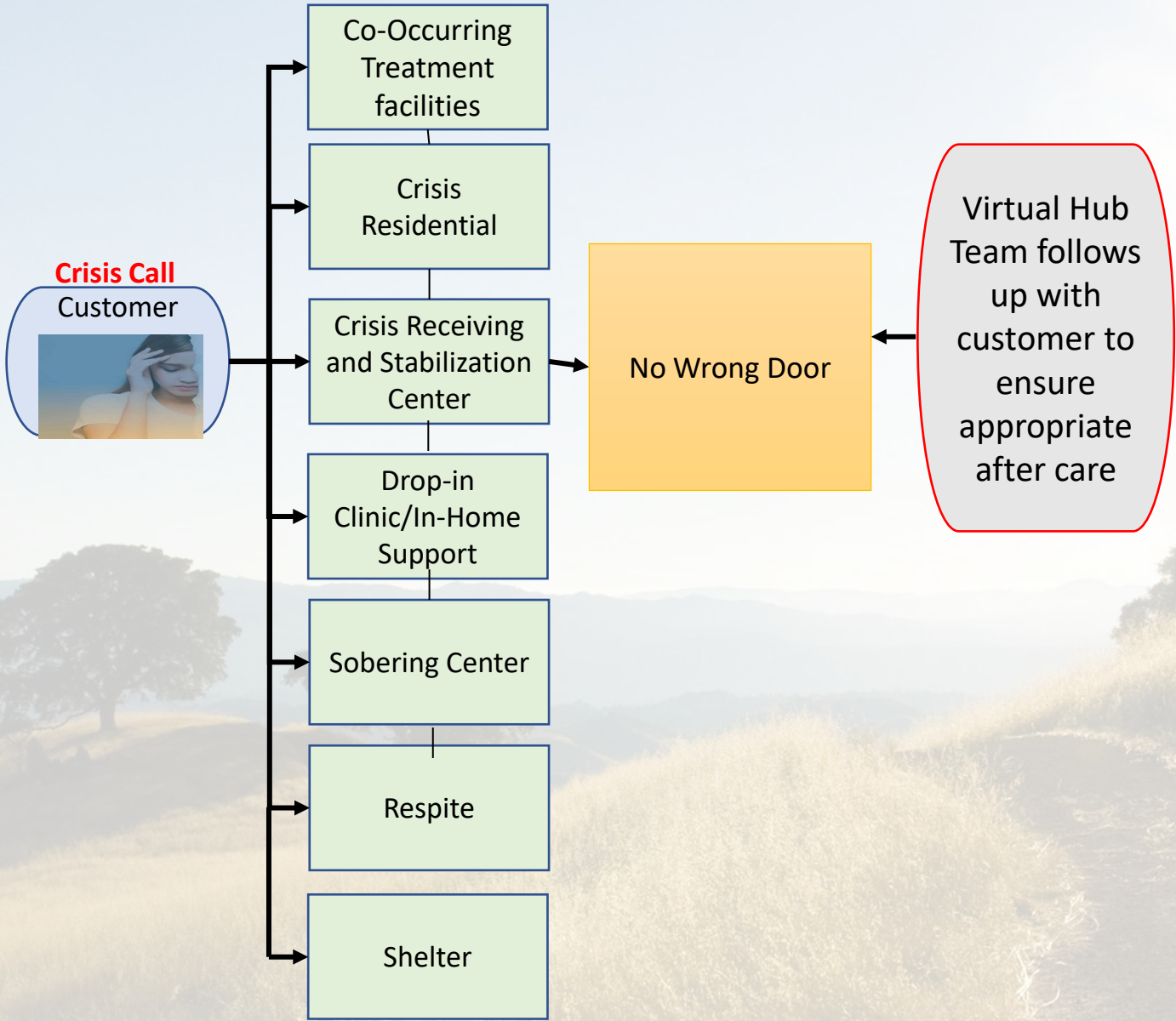
Anyone in Contra Costa County
can access timely and appropriate
behavioral health crisis services
anywhere, anytime



Alternate Destinations



Future State Alternate Destinations Model



Next Steps

Expand and Create Children and Adult services in all regions:

- ✓ Peer-Operated Respite
- ✓ Sobering Center
- ✓ Crisis Stabilization Unit
- ✓ Crisis Residential Facilities
- ✓ Co-Occurring Treatment facilities
- ✓ Shelter and safety for those living with Mental Illness
- ✓ Drop-in Clinic/In-Home Support



Questions & Answers

