



Housing That Heals: Finding a Place Like Home for Families Like Ours

April, 29, 2021

Department of Health Care Services
Director's Office
Attn: Angeli Lee and Amanda Font
P.O. Box 997413, MS 0000
Sacramento, California 95899-7413

RE: CalAIM Section 1115 & 1915(b) Waivers

Dear Ms. Lee and Ms. Font:

As the co-authors of the Housing That Heals white paper issued in May, 2020, we write to share our support for the overall CalAIM concept. We recognize the intent to build off the success of the previous 1115 and 1915 b Waivers and understand the benefits to many county health systems, including our own of Contra Costa. However, we strongly disagree with the decision to postpone the inclusion of the SMI/SED IMD Exclusion Waiver until July 2022. A place holder without promise is unacceptable.

At a time when equity and anti-discrimination are a local, state and national priority, California must move to implement the demonstration waiver that will help to reduce the discrimination and suffering caused by the lack of appropriate treatment beds at all levels of care for our loved ones living with SMI and SED. Our Housing That Heals paper defined the drivers of despair and disparity with both system data and what we call “data of the soul,” which is our lived experience in trying to save our sons and families from falling off every carved out cliff in California’s continuum of care. We also defined a system of solutions. Our focus was not only on our families, but on all California communities that have human beings waiting for access to a bed instead of a tent, trauma, torture and tragedy. Our families and communities simply cannot continue to wait for the state to fix every social, economic, and bureaucratic barrier to care.

The state has had years to innovate, integrate and investigate the finance and delivery arms of the behavioral health systems. We see the good intentions of this effort. As former Mental Health Commissioners, MHSA Stakeholders, state and national activists, we have been part of that journey and have partnered with patience with anyone who will help families like ours. We intend to continue collaborative conversations with all local and state partners who have authentically welcomed us to their tables to consider shared agendas, visions and priorities. We were proud to co-sign the letter of support for the Governor’s proposed \$750 million infrastructure budget item that will signal our state’s intent to build up our community based residential infrastructure. However, we don’t see the IMD Waiver opportunity and the infrastructure investments as either/or decisions. We need a both/and approach to the current crisis of care in California.

Part of our Housing That Heals journey was about finding alternatives to IMDs and locked facilities. We wanted to shatter the myth that moms like us just want to lock up their seriously mentally ill adult children and throw away the key. We wanted to show that it is the system that is designed to lock them up either in solitary cells, IMDs, or in their untreated minds on skid rows. We wanted to find the key that would open doors to healing homes. But, many of those homes will not accept people who are too sick and not medically stabilized enough to live in the community.

As moms of sons who were diagnosed early, received access to multiple public and private services and were deemed disabled by the state and federal government's guidelines, we are concerned about CalAIM's lack of focus on the current SPMH adult population. We acknowledge the spectrum of solutions needed to end suffering in California for those heroically living along the continuum of behavioral health care. We do understand the need to align our Managed Care Plans and Mental Health Plans. However, we don't understand the need to wait any longer for focused attention on the population that has too often been forgotten and "underfunded from the start."

We are still being told that it is just too much of a "heavy lift" to include the SMI/SED IMD Waiver in the current proposal. We were told that in November 2018 when this waiver opportunity first became available. So, we waited. Then the pandemic hit our world and we saw very heavy lifting taking place to save lives. We saw freedoms withheld to protect the safety of our communities. We saw our loved ones rise to top of the most at risk populations to die from COVID. We saw our loved ones forgotten again in the equity discussions. We saw them left in solitary. We saw them locked in State Hospitals or IMDs longer than was medically necessary waiting for a step down bed. We saw them dumped from hospital beds and returned to inappropriate lower levels of care. We saw them suffering on the streets. Everyone sees them now. There is no place left to hide.

Our families know all about heavy lifts. We have been carrying and sharing the weight of the broken, bureaucratic barriers to a continuum of care along with our seriously mentally ill loved ones. We do not want "anyone, anywhere or anytime" to be denied access to the right door. But, without access to both medically necessary and recovery-based services, the human log jam will grow and our loved ones will continuously cycle through the wrong doors.

If we want a California for all, then all must mean all. If we want equity for all, then all must mean all. If we want parity for all, then California cannot wait to apply for the IMD Exclusion Waiver opportunity. If we want a right to shelter and treatment for all, then California must stop waiving the right care at the right time for the stage 4 adult specialty mental health population.

Families like ours and allies across the state strongly support application for the SMI/SED waiver now (see attached.)

Respectfully,

Teresa Pasquini and Lauren Retagliatta
Housing That Heals

https://hth.tinet.com/Housing_That_Heals_2020.pdf