

Below is my response to a survey by NAMI California about the IST system. I am sharing those in total with the full workgroup to ensure that my family story will be considered in any short, medium or long term system redesign in California.

1. I am the proud mom of a Contra Costa County client who has been 5150d over 40 times, conserved by the Contra Costa Public Guardian's Office for 20 years, placed in multiple out-of-county placements, both locked and unlocked. He survived 4 years of off and on solitary confinement as one of the hundreds deemed Incompetent to Stand Trial in this state because they have not received the right care, at the right time, in the right place. He was in and out of the DSH during that 4 year period. He was at Napa on an LPS hold for 9 months before his arrest. Then approx 6 months of IST training at NSH and another 9 months at Atascadero for IST training. Because competency was never restored by the judge(DSH said he was competent but the Public Defender disagreed and won), his first two felonies were dropped and he was sent to CPT's Forensic program with one felony charge remaining. Again, competency was not achieved and the charges were all dismissed and our son was transferred to the Main Unit of CPT on his civil LPS commitment. He remains on that civil LPS while living in the community at Psynergy in Santa Clara County for the past 2 years, paid with MHSA funding. He does not need a state hospital or an IMD anymore but he will likely not be able to live independently. He needs Housing That Heals to prevent a return to the more restrictive level of care. Most Board and Care facilities do not provide the appropriate level of clinical and recovery supports. The Psynergy model is unique and must be spread and scaled.

What is the family role?

2. The family role in the IST process is to provide support to our loved ones, their treatment team, and attorney. It is almost an impossible role to navigate. I was fortunate to have resources, relationships, and knowledge that allowed me to help the public defender, the judge and the DA understand how we could keep both the community and Danny safe and achieve justice. But, it required Contra Costa County to pay for that diversion placement at California Psychiatric Transitions and required CPT to accept him. Both agreed to do so because they felt an ethical responsibility to provide patient and family-centered care in the most APPROPRIATE least restrictive placement. Technically, Contra Costa could have left him in the DSH system but that would have put him back in the IST que. Instead, they invested in doing the right thing and it has paid dividends with our son's ongoing stability and recovery. This pathway should be developed for others. I wrote publicly about our family experience before, during, and after the IST experience because it was the cruelest, most inhumane process and most families do not have the bandwidth to survive it. I wrote the Housing That Heals paper to demonstrate that there are solutions and alternatives to state hospitals, jails, and prisons for families like mine. I will spend the rest of my life fighting for a system of solutions that will prevent the suffering and solitary that my son and family survived. The one size fits all system approach, fails many in California. It is time to focus on funding a full continuum of care for all and all means all.

What was your experience with the DSH?

3. Our experience was good at first and then turned into a nightmare. My son was placed at Napa State Hospital on a civil LPS Commitment when all other facilities declined him access. Once there he did well at first and then it all fell apart due to a lack of coordinating medication history with his county conservator and his family who knew that the medications he was on at NSH would lead to disaster. Sadly, once the treating psychiatrist started listening to us, it was

too late. My son's behavior was out of control. He was placed in seclusion and restraints five times in a handful of days and after being released, he acted out. That resulted in his arrest and his first felony charge. He was determined to be Incompetent to State Trial and sent back to Napa State Hospital as inmate # 201202796 for "competency training." I went into warrior mom mode to save him from state prison. He picked up two more felony charges while in jail. He was sent to Atascadero which was a better program for him and they were better at partnering with our family. But it was 5 hours away from us which meant that we could not visit him as often as we wanted. Luck and heroics helped to divert him eventually. I wrote about it in this blog for Treatment Advocacy Center, <https://www.treatmentadvocacycenter.org/fixing-the-system/features-and-news/3701>. I have also referenced the experience in the Housing That Heals paper, <https://namica.org/community-voices/team-nami-spotlight-housing-that-heals-project-report/> see pages 31 and 52.