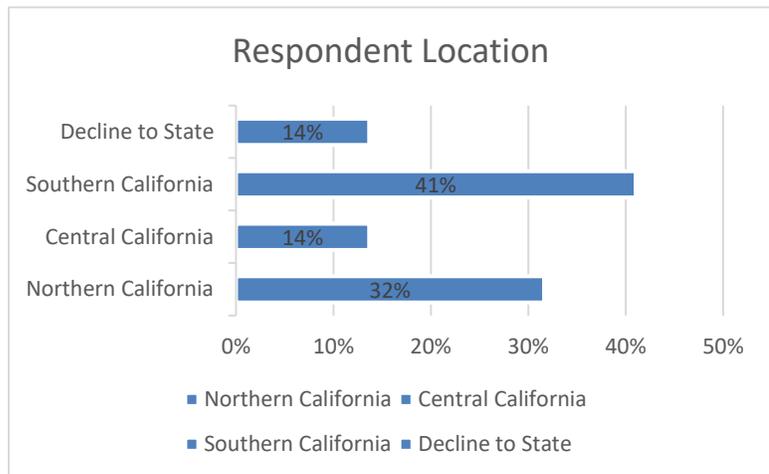


November 2, 2021

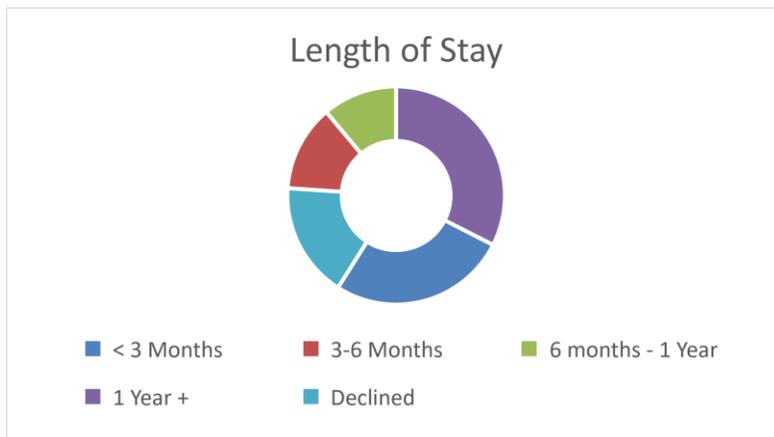
## NAMI California State Hospital/Incompetent to Stand Trial Survey

### Executive Summary

Families are happy to get their loved ones to a state hospital or treatment facility so they can finally get consistent compassionate care. However, the hospitals and programs are often underfunded with caring staff who lack resources to do their work effectively. The IST process feels cruel and exclusionary to many families who are seeking to support their loved ones and are met with bureaucracy, red tape and a care system that feels impossible to navigate.



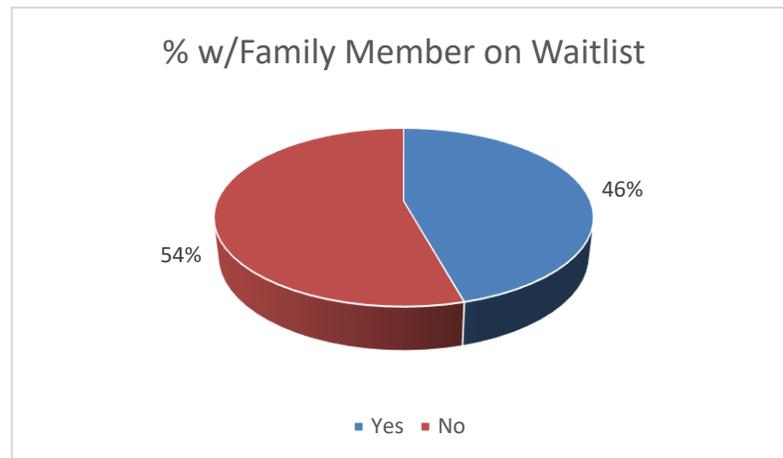
Programs need to be better funded locally and within the hospital system, more care options are needed before people reach the place where they need IST and families need to be much more involved in the IST process from beginning to end.



We had 117 total respondents from across California with a large variation in the amount of time spent in the hospital, as laid out in the charts throughout this summary. Respondents were eager to share their experiences and try to improve the system for families in the future. They view the state hospital system and the IST program as critical steps in care.

## Key Questions:

**If you have had a family member who has been in a state hospital, how would you describe the experience?**



### Key Points Brought up:

1. Lack of Funding for adequate care
2. Caring staff
3. Better than jail/streets
4. Substandard Care
5. Lack of Family Involvement

### Positive Feedback

- Much better than jail
- "It is the first time our son received the sustained medical care he needed.
- The treatment team has been knowledgeable, dedicated and caring with our loved one and we feel fortunate for this.
- "There are many experiences but most important is our our son has received compassionate and thoughtful care from his treatment team from day 1.
- Our family has also received support from many who work at the hospital, doctors, nurses, social workers, administration, to concerns we've had .
- The staff and administration at Napa State Hospital are dedicated and compassionate people who are doing everything they can but they need more support .
- although it was long, it ultimately was what saved my son! Somehow they got him to acknowledge he had an illness, and found a medication that worked for him. He has been on that medication for over 5 years and is doing very well.

- The hospital staff and administration has been both compassionate and dedicated but they are many times constrained by budget issues and sometimes laws. Napa State Hospital runs a monthly family meeting that includes the hospital administrator and a number of staff and have been compassionate and responsive to family concerns, however, they are often hampered by the hospital system that takes too long to make the most basic change needed. Families often bring excellent ideas for change that can make for a more therapeutic environment but we've experienced it takes months if not years, and often never, for any change happen. This is a great loss.

### **Negative Feedback**

- "My son is in jail, going on four years. He is finally on a waiting list to enter into a state hospital for not guilty by reason of insanity. How long will that take? Months, years?"
- This length of time is cruel and unusual punishment. If a person with SMI enters the criminal justice system they should go straight to a state hospital for evaluation, then treatment."
- Only private hospitals 2 week to 1 month
- The hospital is short staffed and they need more financial support to be able to offer the best care possible for our most severely mentally ill. They need additional funding to support programs and to repair the facility where needed."
- After 4 months in a grossly overcrowded rural county out-of-state jail, it took family "heroics" to get him removed and transferred to a state run hospital/mental health rehabilitation center (MHRC), for 10 months, and then, finally back to the Assisted Outpatient Treatment (AOT) program in Contra Costa County.
- Problems;
- Funding; There are many things that could be better with more funding and staff but our hospitals are constrained by the budget \$ and can only do so much with what they have.
- \*Bureaucracy; Hospital administration and families have repeatedly identified issues that weren't working but to get something done, as simple as it may be, can take years. The bureaucracy surrounding change needed is harmful.
- \*It takes too long to get a bed; We need more beds so that people who are very ill get the care they deserved.
- Therapeutic environments: Our system needs to invest in and make our hospitals the kind of therapeutic environments"
- Not great. Social worker very poor, not helpful or very good at communication and being a caring person or giving providing resources. Just wants to keep my brother there forever.
- Very traumatic at first. I believe my daughter would not have gotten better if she was not there.
- "He was sent from Santa Cruz Jail for IST treatment. His mental state was improving (in the short time he was there) in the sense that he was able relate to family, with whom he was at odds before, and seemed hopeful for the future. But his delusions and lack of understanding of charges pending were not fully addressed and he was returned too

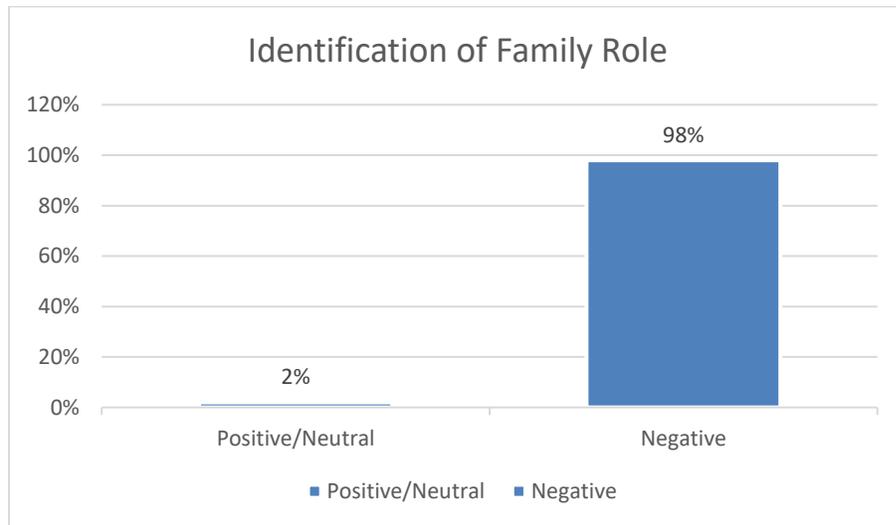
soon to face charges and court proceedings he still did not fully understand. Upon his return, clearly still delusional, he accused his attorney of conspiring with his mother to keep him in custody. Accepted a plea deal from the DA, just to get out of jail. Was released only to continue the cycle of roaming homeless, being mentally unstable and returning to the jail/court's revolving door.

- I can't understand how he could be labeled ""competent"" when he clearly still believes the charges were based on a law invented by his mother."
- 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.
- Sub-standard care and a wasted 6 month opportunity to find the right medication and therapy to start a real recovery. Dr could barely speak English and did not find the right medication for him allowing him to reject an LAI and simply take Abilify which was doing absolutely nothing for him. The Dr wouldn't sign an insurance form for us stating that he wasn't his doctor and couldn't I go to an outside doctor? I asked him if our child was under his care? Was the doctor prescribing and administering medication? He said yes to both questions and I said then you ARE his current doctor. He finally signed the form. No collaboration with our family who knows our child and his medical history best.
- Under-supported, insufficiently staffed, unsanitary (everyone in my son's unit developed a scabies-like skin infection), and woeful waste of beautiful grounds and building resources. Two lengthy experiences produced good outcomes, one did not.
- Family members are not part of the treatment team.

#### **Neutral/No Feedback**

- Some good some bad.. not jail, not as hostile, quieter. Essentially no therapy... A lost opportunity. More respectful treatment and better trained staff, although there is room for improvement there.. no access to doctors and minimal to clinicians.
- Short stay, don't know much about the conditions of the hospital

## Please explain the role of families in the process.



### **Key Points Brought up:**

1. IST is a cruel/challenging process for families
2. Need more family involvement across the board, no role currently for families
3. Families Excluded
4. No effort to include families
5. Impossible role to navigate
6. Feel helpless

### **Positive Feedback**

- None provided

### **Negative Feedback**

- IST is a cruel twist of the criminal justice system. It should be abolished. If a person fits the IST profile, then just admit them to a state hospital for treatment and have them follow the same discharge criteria as everyone else.
- Families must be involved in the IST process more so that our loved ones are not rushed through this treatment time before they are well enough to represent themselves with their attorney. The hospitals do not have enough beds and are pressured to provide treatment for those who are sitting in jail cells for too long and to free up bed space. Our state hospitals should not have to rush people through this process before they are in their right mind and are able to represent themselves in court. We need more beds!
- Role? What role? Families r excluded pretty much unless they are assertive in contacting the PD n DA.

- My son went off his much needed medication and waited a long time struggling to get arrested so he could sit in a solitary jail cell without any treatment, for months and months waiting for a bed to open at the state hospital.
- Family pretty much excluded from participation. We call him several times a week
- Had to put as much information about my family member as to get the right medications and therapy
- I constantly spoke to the Doctor and social worker at parole but they work for parole not for the clients, so they don't work to improve conditions for the mentally sick. They are treated as criminals! I talked to with the supervisond district attorney. Give written a letter to one of the judges that sent her to prison.
- Father was allowed to visit and bring in food at the hospital. No effort was made to communicate with, or involve family in his treatment or therapy. Out of county mother left her contact information with the hospital but never received communication in return. I don't know if he was reminded that he could sign the ROI and I have no way of knowing if the option of MH Diversion would have been explained in a manner that he could understand the benefits of it, also encouragement for treatment depending on the outcome of his case. Both would have been a great service.
- The family role in the 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.
- Families are HELPLESS.
- Visiting the jail at least weekly to give support and observe physical and emotional state.
- Prodding, nagging, pleading with county mental health staff to give medical and psychological attention."
- None

**Neutral/No Feedback**

- Absolutely "mission critical" to avoid a lifetime of "locked in " involvement in the criminal justice system.
- "Question is unclear - during IST process or hospitalization.
- "Hiring and/or coordinating legal representation
- I am not sure what the question is. The family has very little say in the forensic process once your loved one is in they system. Santa Rita Jail is terrible and families are treated like convicts.
- Not 100% confident about the question. Dsh delays until forced to admit. There's insufficient lobbying by governmental agencies for more beds. I don't see families of having much of a role, I bugged my fm's attorney and called dsh to see what the hang up was. No effect. Family should be involved in placements if they will be providing support and visits.
- If IST - not relevant
- If hospitalization - provide support