

Comments by Teresa Pasquini to the DSH/CHHS IST Solutions Workgroup:

I am writing to share my thoughts on the process and product resulting from the IST Solutions Workgroup.

First, I want to begin by thanking all who have participated in this very difficult conversation. I understand the scope of the issue and respect the perspectives and solutions shared. However, there has been a glaring absence of the voices of those of us who have actually lived this nightmare. Token participation of the patients and families with 2 minute sound bite opportunities has not been adequate. While there were very good intentions made to accept information, I personally needed to see a more authentic, transparent partnership between the state, state partners, county partners and community partners in this process. I fear that we have missed the magnitude of the moment and that more human suffering and fiscal waste will be the result.

Before I comment on the IST Solution Matrix Report dated 11-5-21, I want to state emphatically that a population-based equity lens is applied to all people living with SMI and psychotic brain disorders. This is the most underserved, marginalized, and uniquely vulnerable population across all domains. This quote from a recent interview by former NIMH director, Dr. Tom Insel, <https://namisantaclara.org/2021/10/the-future-of-mental-health-according-to-tom-insel/>, calls out the disparity that nobody is talking about,

“We are in the Jim Crow moment for mental health. People, especially those with serious mental illness, aren’t even in the back of the bus. They are left out altogether,” he said. “This is not just a health-care problem. It’s a social justice problem. It’s a form of discrimination.”

“You need to call that out for what it is,” Insel said. “This is the kind of disparity we don’t see in any racial group or ethnic population in America. This is the most underserved population medically in the U.S. It’s the kind of discrimination that shouldn’t be tolerated.”

Dr. Insel boldly stated what families like mine have been experiencing for over 60 years. In order to understand the impact that the drivers of discrimination, death, and disparity have on our families and our communities, the state must hear from moms and families who have had to crawl through glass to save our loved ones from jails, prisons, streets and morgues.

In 2020, I co-wrote a paper with another California mom called “Housing That Heals.” In that paper, we shared our lived experience with California’s broken system of care for people who live heroically with serious mental illnesses. The paper describes how my son and family experienced every jagged edge of every broken piece of the California

mental health system, both public and private. I shared that in spite of all of our efforts and resources, my son ended up in Napa State Hospital on a civil, not criminal, commitment and was then arrested as a patient and placed in the IST human log jam. That experience almost broke my son and our family. But we survived to tell our story and I refuse to leave that “data of the soul” out of this conversation.

As I have shared in my public comments to the IST Workgroup, I am traumatized by that experience. And, that trauma will not allow me to objectively listen to the short and medium solutions which will never move all of the human log jams across our state. Intellectually, I understand the current focus on the biggest bang for your buck solutions. But from a moral, just and ethical perspective, we must stop cherry-picking the low-hanging fruit and reach higher. Sons like mine and families like mine are the high-hanging fruit and we are dying on the vine while the state and counties struggle with politically correct solutions. This must stop being a political and fiscal shell game. In order for any hope for real reform, California policymaking must get data driven, person and family centered and focussed on the forgotten SMI population.

I have reviewed the (See the draft at [IST Solutions Matrix Report Presentation 11.5.2021.pdf \(ca.gov\)](#)) While the data provided in the workgroup discussion has been appreciated, those of us in the community have been without access to the discussions taking place behind the scenes. Position papers are being shared among workgroup members and we hear references about the upcoming “needs assessment” report that is to be released in November. However, those of us who have been partnering with patience for years are again left waiting. We have already waited too long for data-driven, science-based information to drive away our despair. I have studied data from the state and counties for years. It is lacking an equity lens on the SMI population and it simply can not be trusted. Therefore, it is difficult to comment on the short and medium solutions being put forward because I fear that our most severely ill will be left in harm's way.

My son would be one of those people left in the FIST line, sent back to a state hospital, or marched off to a state prison to rot because he had the big scarlet "V" on his back. I am so tired of having our loved ones split into categories that fit the criminal system's narrative of "violent" when in fact, the health and civil systems require violence in order to obtain hospital-based medically necessary treatment before tragedy. One of the number one drivers of the serious mental illness population's prison pipeline is civil commitment laws that require dangerousness to self/others or grave disability before we can intervene to help someone. What other illnesses require people to be dangerous before we treat them?

Before my beloved son was arrested, he should have a "V" on his back for being a victim, not for being violent. Now he should have an S on his back for a survivor of solitary. What he experienced was the cruelest, most inhumane process. Too many

don't survive it and most families do not have the bandwidth or resources to help them 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. We must move beyond luck and heroics in California. 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.

In reviewing the recommendations, it seems that so much is being ignored about the reality of the current state of the non-system. It feels like many "stakeholders" are comfortable "othering" the SMI population. I think Judge Manly was the only one I heard stating that we should not be separating the MISTs and the FISTs because he said that they are the same people with the same illnesses. I am with him.

Of course, SB 317 is a wonderful first step and should be a consideration for the felony population. But does anyone live in a county that is properly staffed/resourced to manage the SB 317 population that is coming in January? I know for sure that my county is not ready. This means that those FISTs will just keep piling up. That is inhumane and unacceptable! I refuse to settle for a system that would have prevented my Danny from living in the safety, recovery, and freedom he is experiencing today. I hope that all of you who are less emotional about this subject than I am will keep thinking of solutions for all. But, just know that a felony charge is not the whole story and must not be a key driver of immediate solutions.

I am grateful to my fellow family members, Mark Gale, Doug Dunn, Linda Mimms, Lynne Gibbs and others who have stepped up and spoken up in this IST Workgroup process. We are not going away and we will continue to push on the status quo and partner with patience because our loved ones are dying, slowly, with their rights on, while solutions are created for **some** with promises for the rest to come **soon**.

As Dr. Don Berwick stated in his 2004 speech to launch the IHI 100,000 Lives Campaign, "**some** is not a number and **soon** is not a time." I refuse to accept that some can have the right care, in the right place now but the rest must wait. We need the numbers now or we will continue to design a circle of suffering for too many.

For the past 20 years, I have dreamed of my son becoming stable, healthy, happy, and UNgravely disabled. I dream of this for my son and all who live heroically with SMI. The #TripleAim4SMI is possible. I am witnessing it with my son. So, I am going to keep focusing on advocating for a tiered system of Housing That Heals and hope that focus will help prevent the human log jams from continuing to pile up across our state and counties.

Thank you,

Teresa Pasquini, Danny's mom

Co-Author, Housing That Heals