Moving Beyond a System of Care Designed to Fail Us

"All systems are perfectly designed to get the results they get." – Don Coyhis

What would happen if we treated substance use with comprehensive, individualized care and support over the long-term? We don't entirely know; we have never fully tried that approach for the general population. We do know that the kind of care provided physicians and other impaired professionals but not the general public yield really encouraging long term outcomes, yet such care is unavailable for the rest of us. We must change this.

I have been thinking about this since listening to the Podcast The Mayor of Maple Ave written and produced by Pulitzer Prize winning journalist Sara Ganim about Shawn Sinisi, a young man from Altoona PA known in the neighborhood where he grew up as "The Mayor of Maple Avenue." As a teen, Shawn was molested by Penn State Coach Jerry Sandusky. He then descended into trauma induced addiction. He was repeatedly failed by the SUD service system and died of an overdose on September 4, 2018, at 26 years old. I felt defeated by the end of the podcast, knowing so many people have worked tirelessly for decades in an attempt to fix the litany of staggering failures it so brutely highlighted.

There are far too many glaring flaws highlighted in this podcast in how people are served for substance use issues to delineate. It reveals a service system that is underfunded. A system in which people receive short duration care at lower intensity than needed provided by a mix of well-intended people and those seeking to profiteer off of highly vulnerable people. One developed in a world that largely defines them as unworthy of help. While listening to the episodes, I thought about all the people I know who have devoted their lives to improving care in these very systems. Candidly, I felt very demoralized by the end of the podcast that despite all their best efforts, this is what our system of care far too often yields. I have watched far too many people die in similar ways. This is the most significant motivator to carry on.

One area that our systems failed Shawn is by not providing integrated SUD and MH care, including services for trauma. My own experience on this came from when I ran a long term licensed long term treatment center for 14 years. There was a state effort to improve public SUD care by integrating MH services. We embraced it. We trained our staff, hired MH counselors, increased our medical and psychiatric services, expanded groups, and generally improved our care for our clients experiencing coexisting mental health conditions. While in some ways it worked, we never got a single extra penny to add all of this care despite all the promises it would come. Funding for care is anemic at best. People get rushed through the system of care, thinly doled out in daily increments justified with mountains of paperwork.

Eventually, all the things we added to serve these patients got cut because we did not receive a single dime to provide them. That backstory does not get told, so the public sees it as a treatment failure and blames providers as incompetent or uncaring rather than more properly viewing it as a funding infrastructure failure. Stigma affirms all the biases of un-helpable people who don't deserve care served by incompetent providers. This is how the tape generally gets played.

The podcast also talks about the failures of Peer Support. Like most human services, they work better if we invest in supervision. We would never dream of sending workers in other professions out to work in such ways. If a student graduates from nursing school, we do not place them into a critical care setting on day one or ever without close supervision, yet this is exactly what we do in the SUD field, often because the field simply lacks the resources to do it any other way. On one of the episodes, the podcast talks about the wild west world of recovery housing. It suggests improving regulation for recovery housing, which sounds good until you consider that the costs of such oversight is saddled on the shoulders of destitute residents who live in these places. High costs push them out onto the street or a flop house if they are lucky. It calls for the integration of SUD treatment with Healthcare despite our recent survey, OPPORTUNITIES FOR CHANGE - An analysis of drug use and recovery stigma in the U.S. healthcare system showing high rates of stigma against people like me. We do not feel welcome in a healthcare system in which we experience horrible treatment and widespread discrimination.

I may sound critical of the podcast, I am not. It is top notch Journalism. The problems identified throughout it are glaring and very real. Yet, addiction is perhaps our most complex condition, and we continually want to frame it and its resolution in simple terms. I suspect for those who listen to it, it will be a sort of Rorschach test for what one sees as broken about our service system. But as a person who spends a lot of time considering how to fix things, I know that there are ten problems hiding behind every simple sounding solution.

There is no one right treatment or even one intervention we can deploy to fix everything. The easiest way I have found to highlight this is to consider cancer. When cancer is diagnosed, we know that what we consider success is five-year remission and we have a long term, varied interventional strategy entirely individualized for what works on a case-by-case basis informed by the best science we have. Cancer is a broad category of pathology that runs from ranges from slow moving cell division at the threshold of benign to aggressive, fast moving, life-threatening cellular mutation. We deploy a full range of treatments and supports when we discover cancer. We focus on long term resolution given the type of cancer a person has, the stage it is in, where it is found and how far it has spread. Complex considerations informed by science.

We know that, like cancer early intervention with an SUD is critical, the longer an addiction goes under treated or untreated the harder it becomes to resolve. At the same time this tragedy was unfolding, I was working to set up a hearing in the General Assembly on how we have lost most of our service infrastructure for young people here in Pennsylvania. Services most often don't occur until these kids' become adults and after they hit the criminal justice system. It is an epic failure. It took several years to set up the hearing and we have not moved the needle very far on care for young people since then, even as we are seeing trends of concern in respect to young people and drug misuse post pandemic.

I have talked about how societal low expectations that people get better set people up by establishing a system of care that provides far less than what people need to heal. We know that anything less than 90 days of care for a person with an SUD is ineffective, and yet we have built an entire care system that only provides a fraction of this to those in need in respect to treatment and nearly nothing beyond it for community support. ***Our treatment system is designed to provide less than the minimum effective dose of care for nearly all Americans!*** The analogy is knowing that one needs 10 days of antibiotics to clear an infection and only providing two days of antibiotics as treatment and then blaming the patient for not healing when their infection rages back.

Perhaps the only direction that makes sense is to examine the stability of long term recovery when it can be achieved and to work backwards from that point to better understand it and to provide more people the resources needed to get there. This is called the Five-year recovery paradigm and is based on the statistic that 85% of the people who stay in recovery for five years remain in recovery for the rest of their lives. To do so, we would need to retool our systems by:

- Establish tools to hold our care systems accountable when disparate, short-term care is provided to ensure that access and duration of services are consistent with applicable laws and regulations while changing these standards where they fall short of what is needed.

- Setting up longitudinal, whole person focused research that examines recovery over the long term to understand what works for whom and under what conditions and use these insights to improve care.
- Full inclusion of persons in recovery in the design, implementation, delivery, and evaluation of services in order to ensure that care meets the needs of those seeking help across the full spectrum of diverse persons seeking help.

Can we envision a system in which people can access residential care without delays or intricate authorization processes, stay there for the time they need, then return to the community to participate in age-appropriate treatment and education? If not, we should ask ourselves why such a vision eludes us. Drug overdoses cost one nation one trillion dollars annually, and alcohol and other drug related consequences eclipses those costs depending on how one measures them. We tend to see this as "those people" who did this to themselves. One of the things that Shawn's story depicts so clearly is that it is not that simple. "Those people" are us.

No one group holds the solution, and there is tremendous inertia to keep things as they are. Our whole system is built to deliver exactly what we are getting right now. It is perhaps too large an ask to reform our whole system. What would happen if we would run a demonstration project in an average community somewhere in America and in that community, we provided everything people needed to get better over the long term? I suspect we would learn that doing so would save money and lives. Until then, it seems that the lives of those who suffer do not matter far beyond the families experiencing these tragic losses. It is time we change that, even if we only tried to do so on a small scale, perhaps it would show us that this would be worth doing in all communities across America.

The most important facet of the Mayor of Maple Street to grasp and act on is that similar stories are unfolding all around us, and we need to act to ensure that the end of these stories include recovery and the kind of life we know can be the probable outcome for people like me when we are given the proper care, for the right duration with the requisite focus on long term support.

We owe as much to every single Shawn who seeks help from our systems of care.

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