A Recovery Disoriented System of Care

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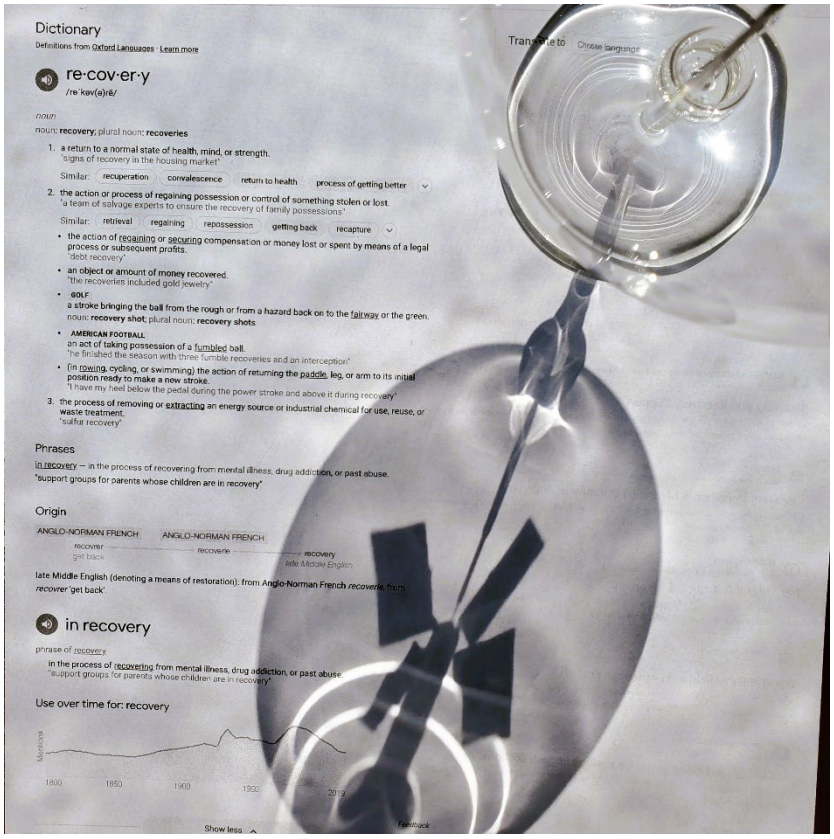

There has long been a dream of a care and support system that would be informed by, facilitated by and funded to offer what people need to heal over the long term from one of our most pressing challenges, substance use disorders. Not incidentally, the number one most stigmatized health challenge worldwide. Such a care system would provide primary and secondary options and long-term holistic support, similar but not identical to what we do for cancer in this nation. This dream has been articulated as a Recovery Oriented Systems of Care, or ROSC. Care that is consistent with the design, duration, frequency, and intensity of what is required across the continuum of substance use conditions in diverse communities nationwide.

We are not close to even having a demonstration model of this caliber anywhere nationally in our public care system. Profound stigma is the barrier to achieving such a system in public sector care. This societal marginalization of people who have addiction or are in recovery creates dynamics in which resources are scarce at the community level. This promotes infighting which creates additional challenges. In my home state of PA, treatment centers are closing as service providers note that lengths of stay are plummeting, and reimbursement rates do not cover the costs of providing even these limited acute care services. Recovery community organizations have no access to sustainable funding in the public sector and rely instead on limited grants. The millions of dollars pouring into states as a result of the opioid settlement rarely reach community organizations because of this profound stigma. We are not seen as worthy or capable. There is an inverse relationship between proximity to addiction and recovery community and access to available resources. Carceral systems and coroners are getting a lot of this money. Grants for academics and hospital networks are measured in millions over multiple years while recovery community groups, when they can access funds, get a few thousands for much shorter spans of time.

By accident or design as a result of the deep, negative perceptions that fuel disparate access to meager funds, infighting to get dollars to push other groups out of the way and survive is the rule, not the exception. We are like drowning people in a lake pushing each other down to climb up and gasp a breath of air. An example of this is the recent draft legislation in Pennsylvania that creates significant administrative burden, restricts who can provide recovery services, public education or even hold a recovery community event to groups sanctioned by the government to do so. It is titled PROPEL and would license all Recovery Community Organizations (RCOs). My sense is that the proposing legislator means well but did not engage the larger community who would be directly impacted by its passage. We would invite more inclusive efforts to support expanding funding for all RCOs.

Under PROPEL, without a government license an RCOs could not hold a public event, advocate for community needs or provide community education in ways we would not dream of requiring for other groups operating with less stigmatized conditions. It asserts to expand support but instead would create a monopoly for a few large, well-capitalized groups who have managed to get most of the grants offered at the state level. This, even as small grassroots organizations with no infrastructure would not be able to afford the administrative burden necessary to obtain and maintain a state license to exist as an RCO under PROPEL. The level of state scrutiny in the proposed bill is also unprecedented.

Creating monopolies to benefit a few groups at the expense of the wider recovery community is not at all what was intended as the vision of a ROSC. It highlights how far away we are from what we need to develop in respect to a ROSC and what authentic representation in developing a ROSC would look like if done properly and in ways consistent with the values it espouses. History also shows us that such measures serve the dominant groups at the expense of the marginalized.

What is a ROSC?

Here is PA, we developed one of the first White Papers on ROSC in the nation. In 2010, the Pennsylvania Recovery Organizations – Alliance along with other pioneering recovery community organizations in recovery and participants from the service community authored the Recovery-Oriented System of Care: A Recovery Community Perspective White Paper. It was a part of the Pennsylvania Drug and Alcohol Coalition efforts and funded by PA Governor's Policy Office, the PA Department of Public Welfare, Office of Mental Health & Substance Abuse Services and the Department of Health, Bureau of Drug and Alcohol Programs.

It was intentional that the funding to envision what the community needed was provided to the recovery community organizations to develop and not token inclusion of recovery groups serving some other vision. The PA ROSC White Paper included guiding principles of inclusion of recovery community members and an orientation of collaborative systems transformation who were largely inspired by the aspirations of the New Recovery Advocacy Movement (NRAM) and transformative processes on the national level. This PA ROSC White Paper came a few years after a similar, more robust effort that led to the 2010 paper titled A Call for Change Toward a Recovery-Oriented Mental Health Service System for Adults, which, among other things established funding for mental health peer services in our state Medicaid Plan.

While some of the aspirations of the PA ROSC White Paper moved forward, most of what was vocalized never reached fruition, principally the recovery community development areas of focus. We have in practice lost our recovery orientation even as the term gets a lot of use. Not just in PA, but nationally. Instead, what has occurred is a gradual reduction in recovery community influence over matters impacting us and professionalization of peer services into a model that essentially orients to a fee for service model and not a community inclusion model. In one of my recent travels, I was talking with a field leader, and they noted how increasingly entities in the peer service space were focused on billing for their own bottom line over the needs of their communities. It is what I also see in many instances.

We have forgotten that NRAM rose out of system failures in the 1990s, fueled in equal parts by a focus on the war on drugs, over professionalization of the field that limited access to the one group of people who want to do this work, recovering people, and broad denial of care by insurance companies. This all occurred in no small part because there was no organized recovery community to oppose what was happening which was itself a byproduct of stigma. Change efforts to correct these failures were modeled after Civil rights and the gay rights movements who were standing up in the face of discriminatory treatment and access to care and basic rights as their community members were dying from AIDS embodied by "silence = death."

Here in PA, we now face a splintering of our community, with an eroded set of core areas of focus to pull us together. Something we hear about as we talk to other groups across the nation. The PA Bill to license RCOs and create a monopoly for a few large, well-funded and influential groups is just our local iteration. Expect to see more such efforts nationally to monetize recovery efforts that benefit investor groups over communities. The broader theme is that deep and profound negative perceptions that exist within all of our institutions keep resources meager, tokenizes our inclusion and creates infighting to keep us all separated while some monetize and commodify our communities. As Don Coyhis, noted recovery advocate known for his lifework with Native American populations, would say, "the system is not broken, it is designed perfectly to get the results it gets."

Reorienting for an Authentic ROSC

Marginalization of stigmatized groups harms our entire society, not just the marginalized groups. This kind of oppression may not be intended or even be visible to those who create it, but it robs our whole society of the contributions that these groups have to offer. We will never achieve the level of healing from the ravages of substance use conditions without authentic inclusion of the impacted communities in their own healing that embrace their own strengths and unique capacities. A system of care that has:

- Leaders in government who possess deep humility and an open ear in respect to the needs of impacted communities and seek to learn from them to build more effective care systems, collaboratively.

- Inclusion of all groups in the development of models of care and support for their own diverse communities.
- Solutions that bring our systems together, not ones that are designed to create benefits for a few at the expense of the many.
- Access to sustainable resources that are equitable for all, including small grassroots RCOs.

Groups from around the nation have been contacting us in Pennsylvania alarmed by the proposed licensing bill for RCOs and asking what they can do to help. From our perspective, history shows us that the only thing that serves to move marginalized groups forward is the establishment of common ground objectives that advocate for the needs of our own communities and humble servant leadership that establishes ways to listen to and meaningfully include contributions and talents across the diversity of our communities. Simply, this is called building community recovery capital.

This kind of advocacy for basic rights in this post could not be conducted by RCOs in PA without the sanctions of the government under the proposed bill. I would be fined for writing this post as an RCO Director without a state license! And the type of statewide RCO we have here in PA for the last two decades would not be permissible to operate. Something we would not even be able to imagine required for gay rights groups, or mental health advocacy groups or Black American groups is actually being proposed for consideration in our state legislature. It is a symptom of infighting created by oppression and marginalization designed to financially benefit a few. If we do not stand up, together against such things we will never move beyond our recovery disoriented system of care and many, many more of us will die from this heartbreaking condition. Our silence also equals our death. The opposite truth is perhaps even more profound as our authentic inclusion would be life saving for our communities and serve to benefit everyone.

Inclusion is the sum of all of us working together. It is a what a Recovery Oriented System of Care in intended to be.

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