

As California began to try in earnest to use the Mental Health Services Act monies to create new recovery based programs, there began to be disagreements over what is and what isn't recovery. The problem boils down to the fact that recovery isn't essentially a practice; it is essentially a culture. Programs can be doing the "right things" but doing them "all wrong". I was asked to conduct a day long workshop at a statewide conference on "Creating a Recovery Culture" not because I knew all the answers, but because the organizers thought that I might be able to help a committed group learn together. I facilitated a day's worth of exercises and discussions, some of which worked and some didn't.

For years I had a laugh line of "Someday I want to see a sign that says 'This facility is psychosis accessible'. I don't know what that would mean, but I'm sure the Social Security Department isn't. To be fair neither are most mental health programs. Sometimes it's like we're running an orthopedic clinic on the fourth floor of a building with no elevator." That was the day I tried to figure out what psychosis accessibility really meant.

First I went around the room asking for examples of handicapped accessibility in their programs and got a long, mostly predictable list of common accommodations for physically handicapped people – ramps, bathrooms, parking spaces, etc. Very few people we see have physical handicaps, but lots of people have mental handicaps, especially psychosis. Then I asked everyone in the room to come up with one thing they do that makes their program psychosis handicapped. After a slow start, momentum started to build and the ideas started flowing. At the next break, I scribbled down on a piece of scrap paper as many of their ideas as I could remember. This article is that list.

By the end of the day we also had the beginnings of what would become my recovery culture progress report card and were well on our way to making the values and culture of recovery concrete and observable.

This Facility is Psychosis Accessible: Twenty Practices

(2008)

The recovery movement may appear to be one of the most idealistic movements in social service today. In the face of the enormous suffering that usually accompanies severe mental illnesses we are attempting to transform the public mental health system into a system with "the journey of recovery" at its core, trumpeting values like hope, empowerment, choice, flexibility, and inclusion as the building blocks of this transformation. Perhaps surprising to outsiders, these seemingly naïve, idealistic transformative values are not being championed by some ivory tower theoretician or protected spiritualist or talk radio host, but from people who themselves have deeply suffered and people who have shared their suffering most closely. This is a movement born from the trenches. Our idealism comes from seeing people actually recover.

As such, the recovery movement is highly suspicious of those who mouth the newest recovery values without seeming to actually change their practices, programs, relationships, and cultures. The recovery movement is, almost paradoxically, an extremely practical, pragmatic movement, focused on doing

“whatever it takes.” Throughout the country we are trying to promote actual practices that promote our values and are not easily placated with pleasant proclamations alone.

The wider disability movement promoted the values of including people with disabilities in daily life, and the ideas of creating opportunity and accommodation, with the mandates in the highly regimented, strongly enforced Adults with Disabilities Act. Every one of us who receives any federal funds or certification can easily name a number of very practical “handicapped accessible” practices that we’ve included in our programs, often at considerable expense and inconvenience. We do this for the few physically handicapped who we serve because of the ADA mandates, while generally ignoring providing accommodations and opportunities for the most common disability the people in our programs are living with – psychosis.

I recently asked a sizable group of mental health staff, consumers, and administrators who are interested in promoting recovery based program cultures to describe practices that they’ve developed to make their programs “psychosis accessible.” After some laughter and head scratching, they shifted to a psychosis accessible perspective (which most agreed would likely be easiest to see by people who are psychotic, just like issues with wheelchair accessibility are most likely to be seen by people who are actually in wheelchairs). They created this list of psychosis accessible practices they do now:

- 1) Since psychotic people may have difficulty consistently tracking time and making their appointments, some programs have flexible hours, various reminder supports, and accommodate walk-ins.
- 2) Since psychotic people may have problems trusting strangers, some programs try to create personal relationships with them instead of maintaining professional distance, basing trust on personal trustworthiness rather than just on professional competency and expertise.
- 3) Since psychotic people may need support when their clinician is busy with others or otherwise unavailable, some programs make an effort to have multiple staff in a team all create personal relationships with each person they are working with.
- 4) Since psychotic people may have crisis and need help outside of normal business hours, some programs have the team together create after-hours accessibility rather than referring the people they work with to strangers in a separate emergency service.
- 5) Since psychotic people may not agree that they are psychotic or not want to accept the implications and stigma of a psychotic diagnosis, some programs offer services without a mandated diagnostic assessment and illness driven treatment plan. For example, some programs do not require medication compliance to receive other services and supports.
- 6) Since psychotic people may focus on other problems in their lives instead of mental illness treatment, some programs integrate mental health services within the umbrella of other social service and health care agencies.

7) Since psychotic people may have problems with self reflection and taking responsibility for making changes to improve their lives, some programs offer charitable assistance without demands while they are engaging people in more collaborative treatment.

8) Since some psychotic people don't want internalize the role of mentally ill patient, some programs offer assistance to people while they are in other roles, for example, day laborer, or senior citizen, or teen, or art student.

9) Since some psychotic people live in cultures that have distinct ways of understanding and responding to what we understand as psychotic mental illnesses, some programs explore people's cultural backgrounds and attempt to offer services and support that works with their cultural framework and experience.

10) Since some psychotic people display overt behaviors that are stigmatized and rejected by our communities, some programs actively advocate for more understanding and inclusion in their communities and actively develop community opportunities for belonging.

11) Since some psychotic people are sensitive to our dehumanizing, stigmatizing way of perceiving and talking about them (perhaps even finding this list offensive), some programs are vigilant and continuously work on their own internal prejudices, segregation, and stigma.

12) Since some psychotic people experience substantial barriers to interpersonal communication and connection, some programs go out of their way to create a warm, welcoming, friendly environment.

13) Since some psychotic people don't perceive themselves and their goals in the same way staff do and may reject staff generated goals and services as a result, some programs have them choose the goals and services they want. Some programs provide substantial education and guidance to support people to improve their ability to make choices.

14) Since some psychotic people have difficulty coordinating complicated processes, some programs provide case managers to assist in navigating, linking to, and obtaining services and supports and may even at times eliminate some steps in the process, for example, by providing medication samples instead of making people fill prescriptions at a pharmacy.

15) Since some psychotic people may have trouble following impersonal treatment plans and coordinating services from strangers, some programs engage people in personal relationships and build their plans and services on their relationships with staff.

16) Since some psychotic people have trouble relating to authority figures or mental health professionals, some programs hire people with psychosis or other shared experiences to make it easier to build a connection.

17) Since some psychotic people have difficulty coming to mental health program buildings for a variety of reasons, some programs meet them in the community or in their homes.

18) Since some psychotic people have narrowed their personal contacts to just their families and rely on them for many things, some programs include family members in their engagement and services.

19) Since some psychotic people behave in ways that are difficult for staff to connect to and collaborate with, some programs reduce behavioral requirements, for example, to be stable or ready, to offer services and have staff who are comfortable with psychosis, “meet them where they’re at,” serving them even while they are behaving psychotically. Staff may be combined into a “multiexperiential team” together able to compassionately relate to a variety of people who may have experienced a lot of rejection and professional distancing.

20) Since some psychotic people can be very emotionally draining and difficult for staff to empathize with and work closely with, some program’s staff strengthen themselves emotionally, support each other, and “ground themselves” in order to be better able to open their hearts compassionately to the people they’re working with.

As this list grew, we realized three things: 1) “This facility is psychosis accessible” is not just a one-liner. Practices that promote psychosis accessibility can be described, defined, mandated, and audited. 2) If we spread our thinking to other mental disabilities, for example trauma, substance abuse, depression, etc. we could develop practices to become more accessible to all the people we work with, and 3) We really have made a lot of progress over the years. That’s an impressive set of accommodations all of which are presently being practiced somewhere. What’s needed to make them universal is to build them into the federal infrastructure like the physical disability accommodations have been.