CTC Family Feedback 12.5.23

Convened by Jerri Clark of MOMI and Candace Joyner of OJD

Twelve family members were present

Tearful, raw, angry… Several commented the next day that this discussion wrecked them and left them discouraged.

- Concern that changes will never come and that their stories will be "heard" but won't galvanize real change.
- "Thank you for the meeting last night. I am haunted by it, had trouble sleeping."
- Families want to hear back from the CTC about how their words are received and considered. **They want a direct and specific response.**
- "These stories are appalling and frightening."

Comments about Oregon's Commitment Standard:

- **"You shouldn't have to kill somebody to get mental health treatment, but that's what my son did," said dad.** *(Mom's memorial is the same week as this listening session)*
- Oregon requires violence for a brief hospitalization yet never keeps the person long enough to resolve the psychosis that led to the violence, discharging back into danger.
- Providers tell us: "Judges will not approve it" as the reason for not filing a commitment petition.
- "Violence has to occur in the moment…. There is nothing anyone will do unless there is an extreme risk of harm."
- "My son had to beat me up," says mom who described PTSD throughout a family, including a younger sibling who watched her mother almost killed by her brother in psychosis and now struggles with complex mental health issues and suicidality.
- "The definition of dangerousness is insane and is causing horrible suffering."
- Adequate care for an adult child "required a crime of kidnapping."
- "You have to commit a crime in a snapshot moment of time."
- "We wait around for disaster."
- "Compassionate professionals cannot beat the system any better than we can."
- "Why does my son with mental illness have to go to jail?"
- "The civil commitment standards must change to clearly allow for commitment for the SMI before they kill people… As E. Fuller Torrey famously said it cannot be that they can only be committed if they are 'killing themselves in front of the doctor or trying to kill the doctor.'"
- "We need to get people committed when they have untreated psychosis. They will almost never consent or do it themselves. Anosognosia is too prevalent."

Barriers

Anosognosia

The involuntary system isn't built to properly account for this common symptom as the reason that a person in desperate need of care won't volunteer for that care: "**The system is protecting our son's civil liberties over his human rights.**"

Families are told by some providers to wait for their loved one with SMI to get sick enough to "realize" their level of need and eventually seek care. This is an error that disregards the reality of severe mental illness and anosognosia.

"Anosognosia is a broken brain, and you cannot expect it to get better."

No access to medication against objection

Family whose son killed his mother watched his rapid and steep decline and were told guardianship was the only option: His now dead mom was his guardian. She couldn't do anything to ensure his psychosis was treated even when a hospital kept him involuntarily for 11 days because he was so dangerous to self and others. He refused treatment due to anosognosia/paranoia/psychosis and staff said: "We cannot ethically treat him." The murder occurred shortly after discharge.

Lack of safe facilities

A hospital provided voluntary services for the young man who eventually killed his mother earlier in his illness. That hospital witnessed his first, worst symptoms as he spiraled into a full-blown first episode psychosis in their care. Recognizing the level of risk, they tried to send him back to an emergency department instead of securing him properly in their psychiatric facility. During the bungled change in plans, he stole a badge and let himself out and was not pursued. His escape without clothes or resources caused physical injury and further trauma. The family tried to patch him up and watched him slip further from reality and safety without any professional intervention available.

Catch-22s

"Even if your therapist tells you to take your loved one immediately to Unity Health, Unity Health will tell you that you have to start at the ER and Unity will only take your loved one if the ER says. And the ER does not say because apparently the Unity Health admission standards are impossible" (caught in the act of trying to kill oneself or someone else).

Poor quality of care

"Abysmal" discharges are leading to repeat cycles through traumatic hospitalizations, suicides, murders, and often arrests.

Inability to access a proper diagnosis, medication, evidence-based care: "There are no services."

Poor or no services are explained as a way to provide "freedom" for the ill individual to figure it out on their own: "Policies of least restrictive care have failed our children."

Other Barriers

- Insurance companies are not accountable to follow parity laws.
- Some critical services are unavailable on weekends.
- "Oregon is the most horrific place to practice psychiatry."

Current Workarounds

Guardianship

Many families say providers advise that guardianship is the only way to get assistance—even the most extreme symptoms of psychosis aren't going to be enough unless they are guardians.

With guardianship some families have been able to get their loved ones hospital beds, but, from the dad whose son in psychosis killed his mom: "Guardianship did not get us TREATMENT."

Privilege

Quality of care depends on "who you get" in the provider world. Provider opinion, energy, and work ethic might sometimes lead to something, but there are no consistent protocols.

This system of "favors" worsens inequities and promotes privilege. Some families agree that they got "something" due to privilege.

Leave Oregon

Families are guided by providers to take their loved ones out of state to access quality care.

Families pick up the slack

Families file restraining orders to protect themselves while their children with unrelenting psychosis become violent enough to meet the commitment standard. This workaround generally ends in family members calling police to have loved ones incarcerated. Then the pathway to treatment is a slow slog through Aid & Assist and/or PSRB, which families describe as the only meaningful option in Oregon.

Providers put pressure on families to take care of the fallout from untreated severe mental illness by providing housing, "counseling," care management, and accepting the inherent risk to themselves. Almost all raised hands that they have been physically injured by loved ones with poorly managed SMI.

Providers refer families to advocacy organizations for their concerns about loved ones with untreated SMI: "NAMI is not a doctor!"

Criminalization

Mental Health Court is the only option Oregon has to place someone and it requires a crime.

The PSRB is the best option for actual services, but “to get that you have to almost kill your mom” and then two psychiatrists have to agree—in this case they didn’t, so even those services were denied, says a mom who almost didn’t survive an assault by her son.

Parents pay many visits to mental health courts… “I watched the judge struggle. There was obviously no place to put all these people.”

Suggestions

<u>Follow the lead of more successful states</u>

One couple described how their son was able to access a higher level of care, including inpatient and outpatient commitment, in another state (NY) that stabilized him for years. In NY, his untreated psychosis was enough to demonstrate his risk of harm: “Court-mandated medication was lifesaving and isn’t available in Oregon.”

From a family member/physician who at one time observed a good working model in New Hampshire: Court commitments were 2-5 years, with inpatient stays of 1-3 months. The length of inpatient stay depended on the severity of illness as well as dangerousness. The system worked to keep people stable in the community; money flowed into the county when a person was being served in the community or to the state hospital when a person was there. Each county had a community mental health center, and everyone had a case manager, a psychiatrist (back in the day before PMHNPs), and other key team members for a whole-person approach. Primary care providers collaborated with behavioral health providers. Forensic patients were served within a special forensic unit, allowing beds at the state hospital to serve civilly committed patients: "There were non-hospital crisis centers for voluntary patients… more like what Unity was dreamed to be.”

<u>Use psychiatric holds more effectively</u>

A psychiatric hold needs to be a period of time for providers to gather information and medical history to make a case for an individualized treatment plan to help a person stabilize out of psychosis. Holds are currently used to rally a defense attorney who is there to “win a person’s freedom to die.”

<u>Improve training</u>

County professionals responsible for upholding commitment standards need much better training and monitoring.

<u>Consider history more clearly in commitment standard</u>

Patterns of inability to care for oneself due to psychiatric deterioration need to be important aspects of the commitment standard.

Family history needs to be taken seriously: “Families are dismissed while investigators fail to use strategic skills to collect critical information.”

Lower the involuntary treatment standard and include accountability

Provide outpatient commitment to uphold individual civil rights: “Lack of support disempowers a person’s ability to self-manage and removes their rights and liberties.”

Create laws that give the medical system responsibility to serve the very ill people who fall into their care: “Hospitals dance to what they’re going to be held accountable to.”