

**Commitment to Change Workgroup Feedback Session
Families of Loved Ones Living with Severe Mental Illness
April 15, 2024**

Meeting notes provided by Jerri Clark, CTC Workgroup Member

Oregon Families Speak Out 4.15.24

“As parents, we’re left out...” and forgotten, despite being those who care the most and work for free, for a lifetime.

Legal standard means families are told:

1. You are getting in the way by helping
2. You need to put yourself in harm’s way

Grave Disability is an impossible bar

When we feed and house very ill loved ones, they won’t meet the standard: “Civil commitment is not available when parents are taking care of a family member’s basic needs.”

Families are in an impossible position. We are told to give up, back off, and abandon loved ones in order for them to access medically necessary treatment due to severe functional impairment. But abandoning them to the streets doesn’t usually work either: “He couldn’t care for himself or manage his activities of daily living. That doesn’t meet criteria.”

Harm without violent intent doesn’t lead to treatment. Example: Causing a very dangerous car accident during a psychotic episode wasn’t enough to elicit any mental health intervention for one mother’s adult son with schizophrenia.

Being arrested for non-violent offenses that show risk of harm is not eliciting mental health help. Example: “My adult bipolar daughter put herself in danger by banging on people’s doors and windows mostly at night. She could have been shot, but fortunately homeowners only called the police. She got arrested for that THREE TIMES [within one week]. She was released within hours. SHE IS A DANGER TO HERSELF. She’s NOT violent at all. Please help ‘define danger’ not only to law enforcement but all authorities.”

“My [son] couldn’t cook for himself or care for himself. He’d use a rice cooker once and throw it away instead of cleaning it. [Calling county crisis] is a complete utter waste of time. He has to physically attack someone.”

Co-occurring substance use disorder seems to be an excuse to not treat, instead of evidence of extreme and additionally complex illness. A nephew with SMI: “People thought it was just drugs, so he couldn’t get mental health treatment. It wasn’t just drugs. He’s a very sick young man.”

A homeless person, well known by locals to be severely mentally ill, was crushed in a Coos Bay parking lot where she was apparently sleeping. The nurse who inadvertently drove over her also has a shattered life. What criteria are required for grave disability if this woman didn’t meet that standard?



[Woman killed after being hit in parking lot](#)

Apr. 20—A 20-year-old woman was killed when she was hit by a car in a parking lot in downtown Coos Bay on Tuesday morning. According to Deputy Chief Chris Chapanar, Raven English died at the scene when she was hit by a car in the public parking lot on the southeast side of Commercial Avenue and North 3rd Street. Chapanar said police received a 9-1-1 call at 10:24 a.m. and arrived on scene ...

news.yahoo.com

Only option left ... wait for them to hurt us or attempt suicide:

"I was locked in my bedroom and telling [providers] this is not going well. They said, *If he beats you up, kills you, or hurts someone else, then we will do something.*"

Another mom: "When the voices start attacking [my son], he goes to do battle...He had weapons...I talked to the police but because he had no adult diagnosis there was nothing I could do...He was hiding his weapons from me because he knew I would take them away... He thinks government people are spying on us behind our eyes. ... He was punching me and not stopping when I asked him to stop. Because of the bruises on my arms, the judge believed me and granted a protection order. I'm the only person trying to help him, so I didn't want him blocked from me, but I didn't want his guns returned to him... He's smart and crafty... His psychosis clicks on and off... and whether he knows who I am also comes and goes... [when the psychosis is really severe] he has scary, off-the-charts aggression."

Violence involving a bow and arrow eventually led to a commitment—and luckily no one was severely injured: "Stopping tragedy shouldn't be up to luck."

Upon discharge another mom rescinded her restraining order because there was no place for her son to go: "Within a few days he was beating me up... the [outpatient] provider said, *You're in a bad spot.*" The violence eventually led to an arrest: "Why does my son have to get arrested and go into shackles to get help? We have so much trauma!"

A mom had to testify before a grand jury and tell her story: "I didn't know I could cry that hard. My son had three near-death experiences, plus beating me up. At one point I thought, *Why don't both of us just go ahead and die?*"

Much time spent watching and waiting in court, this mom knows her story isn't unique: "If you want to know what we're doing in Oregon, just go to the court room. It's appalling."

Legal standard of imminence disregards obvious dangers

In the weeks that led to a 5-day hold, an adult child "talked about gutting me or disemboweling me" and threatened to murder a child relative, although that threat was disorganized and strung throughout a psychotic "word salad." Parent shared that history with staff during the inpatient 5-

day hold, but paperwork for a commitment wasn't filed. Parent was told that the information did not show imminence of danger and that this information from within a month was "too old."

A family member who is also a provider notes that case law has risen the bar to a standard that makes protection of life impossible. To petition for commitment: "You have to testify that this person is going to die in the next 23 hours and 59 minutes if you discharge them."

Commitment requires everything to fall apart, then takes apart anything left standing

Insurance and benefits: Medical insurance is canceled during a commitment, so medication cannot be consistently maintained after discharge. Disability benefits are also canceled, so basic life is often unworkable post-discharge unless families provide everything: "It's neglect!"

Trauma: Trauma from the extreme level of illness required, followed by poor quality of care, adds layers of complexity to the ongoing prognosis, lowers chances for recovery, and adds elements of dangerousness post-discharge. Although imminent danger was required and the reason for the hospitalization: "They tied him down because he was combative." The fight or flight response was heightened after that and made him more combative back home.

Housing: Most people lose their housing in the process of becoming imminently dangerous because of eviction, lost benefits, broken relationships, or something else. After losing ability to care for basic hygiene, one young man "came in with lice," so his apartment had to be fully fumigated before it was habitable again. His mom had to remove her order of protection and take him home so he wouldn't be discharged to the streets.

Poor medication management: Medication errors and lack of access to medications post-discharge have caused life-threatening complications for several of our families.

HIPAA barriers: Extreme nondisclosure policies are problematic for families trying to house loved ones with illnesses and symptoms they don't even know about: "They didn't tell me he was addicted to fentanyl." That nondisclosure added layers of danger when her son came home while still in psychosis and addicted.

Families are blamed and shamed while early intervention services are unavailable

Son and mother were bullied by staff at school when son showed prodromal symptoms of psychosis: "I was told more than once that I was not a good mother by the school." Providers told her to "wait and see" and said, "Sorry for your luck."

Mom was blamed for not mothering him correctly instead of being provided any assistance. "When he finally broke from reality...and was hearing things, I knew it was schizophrenia. I thought, *there must be some help for me somewhere now*, and I found out it was zero." Her son's first psychotic break meant an encounter with police and a provider's recommendation to remove him from her home: "I had no frame of reference, and nowhere to go... It was a living nightmare."

"I was gaslit, stonewalled, shamed."

At the same time, our loved ones with SMI are also shamed and blamed by people who do not understand brain-based illnesses and how they cause mental regression, functional incapacities, and behaviors related to a disconnect from reality and are not conscious choice-making: “None of this is their fault or choice.”

Standards don’t acknowledge realities of a psychotic illness

Arguments that people need to be left to make their own life choices show a lack of understanding about SMI, which in acute stages has already stolen a person’s capacity for choice. Voluntary services aren’t accessible to those patients, so the involuntary system becomes the only doorway into medically necessary care.

A commitment standard that requires violence means that violence is the *only* doorway into medically necessary care for those with the most severe illness conditions.

Guardianship is expensive, restrictive, and no guarantee of better outcomes

Guardianship is an unpredictable and expensive stopgap in Oregon. Many families try this route, with mixed results. There isn’t a way to file without the help of an expensive lawyer, so there are inequities.

Hunter’s wife had guardianship before being killed by her son in untreated psychosis. Even guardianship did not help her get treatment for her son: Violence was still the required element for treatment eligibility.

System doesn’t account for disabling symptoms that make independent living impossible

“If my son gets out, he will die. I live with this fear every day. He’s not okay, even on the medication. It’s years and years before he will have a possibly more independent life. What we went through from high school to today, no one should go through that.”

“If people die, it’s just the cost of doing business...The indifference is shocking.”

Incoherent system, rapidly getting worse

“It is so much worse in Oregon than it used to be. It’s unbelievable how much worse it is. There are evidence-based tests you can do to predict what level of care and assistance a person needs but in Oregon they don’t do any of those. They just say the person has to fail.”

“Case law has ruined the mental health system in the state of Oregon.”

While considering lived experience, please acknowledge truth of SMI

From a family member who is also a licensed psychiatrist: “People who are psychotic cannot form memories. When people tell you about what they remember it cannot be accurate. They aren’t lying but they cannot give you accurate information about when they are most ill.”

Looking ahead, solution building...

Historically, attempts to lower the imminence standard have been shut down. Families have expertise about how to gauge when somebody’s illness symptoms are becoming dangerous, but our voices aren’t heard. We need the law on our side.

“The only solution is legislative. Expanding the ability to do commitment and to look at more than imminence is key. None of it matters if there aren't more than 3 options.”

Treatment options need to be expanded alongside improvements to the law. “If our only treatment option is inpatient at the Oregon State Hospital...no matter what we legislate it's not going to make any difference if there are not treatment options.”

If the concern is that somebody might abuse the commitment system: “Then create repercussions for someone making false testimony.”

The status quo cannot be maintained:

“People are dying.”

“You're guaranteed to fail in the current system.”

Copy of email from family member who was unable to attend the CTC Workgroup Feedback Session on 4/15/24, responding to questions posed by CTC Workgroup member Jerri Clark:

- *What do you think is important for the state to understand about what's working or not working in Oregon's treatment system for someone with severe mental illness?*

I would say it's important that they understand that most of it isn't working!

I think the crisis line and their mobile mental health teams are a wonderful concept.

However due to the laws currently in place nothing can really be done to truly help families or individuals struggling with severe mental illness. Those with severe mental illnesses are 50-60% likely to have a subsequent condition called anosognosia, which means that they have no insight into their mental illness. Oregon law in attempting to honor citizens civil rights have crippled people who lack insight into their illness as well as their families.

The current criteria in Oregon law allows a person to be treated for a mental illness against their will ONLY if they are experiencing an emotional disturbance and are imminently dangerous to themselves or others. Never-mind if they attempted suicide 72hrs prior to this or they escaped from the hospital while on a hold- legally they are free to go! The judicial system has left individuals unprotected and their families and community helpless. It is neglectful at best and at worst- deadly.

I think law enforcement is better trained to deal with people with mental health issues. However despite that being true the laws they are given to assist people with mental health issues gives them little to no authority. They are part of a catch and release system that is in place and leading to death and loss that could otherwise be avoided.

I think there are a lot of programs with no availability & wrap around services are nonexistent. When trying to access services for my loved one I was told there was no availability. In most cases for years! I was told that direct admits into residential programs were not the way it was done. That access or referral came from the court or from hospitals and that the 'next time' my family member was hospitalized i could have a social worker or medical

professional refer them. I pointed out that my family member suffered with what most people with SMI suffer with, which is delusions & a lack of insight into their own illness and that 'next time' they were admitted to the hospital they might be dead or end up dead because that would mean they had attempted to commit suicide again.

- *What should we know about your family's experiences with law enforcement?*

I have had positive experiences with law enforcement in regard to my family member. They saved their life with both of their suicide attempts.

- *What resources are most helpful in a crisis? Can you give examples of what worked or might have worked had it been available?*

In a crisis a true crisis law enforcement has been invaluable & the mental health crisis line. It would be most helpful if they could provide assistance by involuntarily committing and treating those who are mentally ill.

It would be helpful if secure transport for people with mental illness was available. As a family member who has sought guardianship- I found that despite having the authority to have a family member placed in treatment and treated against their will I had no way to get them to treatment if they remained unwilling. It left me right where i started at the mercy of hoping my family member isn't successful in dying by suicide. It goes without saying that this service would be unnecessary if the laws allowed law enforcement to assist.

- *How has Oregon's legal standard for civil commitment impacted your loved one with SMI?*

It has endangered them, those around him and has allowed his illness to worsen by going untreated. The research on leaving those with severe mental health issues untreated, especially early on are undeniable. They deserve better and we deserve better. I feel that the state is avoiding their duty and obligation.

- *Do you have thoughts on how the laws should be changed?*

Yes, I think that the criteria for intervening and treating those with mental illness who lack insight and are dangerous to themselves and others should be reasonable. I think individuals should be treated longer and have more wrap around services made available- ie court ordered residential placements & court ordered outpatient treatment with housing and medication management options. Allow family or public guardians to oversee their care given proper guidelines. Hospitalizing then simply releasing individuals with SMI is fruitless.

- *What else does the state need to know about your family's experiences?*

The state has made it impossible to help keep my family member safe. Impossible to get them the care they need & it has been a living nightmare inside of a nightmare illness. No one is winning in the current system. The individual doesn't win because they are unable to function in society, they are at high risk of self-harm and death (1 out of 10 people with schizophrenia left untreated die by suicide) & they often end up homeless and are taken advantage of by others. The family doesn't win because they can't get their loved one help, even when they have the resources available because state laws won't allow it. The community doesn't win because

many of these individuals end up on the street homeless. This is unacceptable & our state is suffering.

April 13, 2024, letter from CTC Workgroup member Jerri Clark:

Hello fellow CTC members,

After our meeting yesterday I spoke with Hunter Graham, the Portland man whose wife was murdered by their son with untreated psychosis after the system failed to care for him. Teresa was a CTC constituent. Her feedback is included in data gathered from surveys sent out prior to her death last October. Last week Hunter was interviewed for a radio broadcast. Link is below:

Please listen.

Hunter shared his story about the family's many attempts to get help and the barriers that led to his son remaining untreated and his wife dying by strangulation. He also talks about how his son is finally getting good psychiatric care at Oregon State Hospital—where he's "waking up" to the reality of what happened. Hunter's clear narrative explains how Oregon requires violence for mental health intervention instead of working to prevent harm.

Before the murder, Austin was detained in a hospital because of his mom's guardianship but not treated for his acute psychosis because he didn't want treatment. On this radio broadcast, Hunter explains that hospital staff had a plan to use "behavioral health" strategies to help Austin "realize" his illness. This is a complete misunderstanding of severe mental illness and the disabling symptom of anosognosia, a form of brain damage that makes realization of illness impossible. Hunter explains how his son failed the "safety" part of the behavioral health plan by killing his mother. It seems that violence was the provider's plan for next steps.

Required violence is funneling people with SMI into the prison pipeline, where Oregon's best mental health care is finally available for extraordinarily unwell and traumatized individuals who can only recover to return to completely broken lives. Austin's dad is now fighting to keep him hospitalized instead of back in jail. When he's finally well enough to understand what he's done, Austin will be on trial for murdering his mother.

This story must galvanize a change in Oregon's approach. Here is the link:

[Deadly Inadequacies of Mental Health Care | KBOO](#)

Other endangered families in Oregon news

A consistency in these stories is that the person with SMI is immediately found unable to "aid and assist" in their own defense after being charged with a horrific crime, but none were "sick enough" or "dangerous enough" prior to the tragedy to meet criteria for involuntary treatment/commitment. This is a system that requires violence instead of preventing harm! Families cannot be the only ones trying to prevent tragedies. We need the system to protect public safety, our safety, and the safety of our loved ones with SMI.

A local source has seen an affidavit from a deputy who was told by the uncle, prior to the murder, that his nephew would have to kill him in order to receive help. He was correct.



[Slain man sought psychiatric help for his nephew](#)

COQUILLE — Details included in the affidavit against Lucas Mark Perkins, 36, accused of murdering his 64-year-old uncle Richard Perkins, reveal that the uncle sought multiple times to get mental

theworldlink.com

Alexis Bergquist stabbed her mother to death, found unable to aid and assist



[Murder charges dismissed for North Bend woman accused of stabbing mother in 2019](#)

The Coos County District Attorney dismisses murder case against Alexis Marie Bergquist due mental illness. According to the DA, on December

kpic.com

Kevin Yates killed his grandmother, found unable to aid and assist



[Murder charge against Coos County man to be dismissed](#)

The Coos County District Attorney says a murder charge against a man for causing the death of his grandmother in Coos Bay will be dismissed due to an Oregon law that says before a defendant can be prosecuted for an offense, the defendant must be able to mentally aid and assist in their defense. The DA said he has filed a petition with the Court asking that the man "be declared extremely dangerous person with a mental illness. "

kcby.com

Oen Nicholson, who allegedly killed four people and committed other crimes, was initially found unable to aid and assist. Local source with knowledge believes he's now considered stabilized enough to face his charges: [North Bend murder suspect may be unfit to stand trial; Coos County D.A. contests finding | News | kezi.com](#)