CTC Workgroup Feedback Session with Individuals with Lived Experience of Psychiatric Holds
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Facilitator: Chris Thomas; **Workgroup Staff:** Debra Maryanov, Brianna Navarro
(Attendee names withheld for their privacy)

Chris Thomas welcomed attendees and provided a brief overview of the Commitment to Change Workgroup. Two people with lived experience with psychiatric holds were present. Chris noted that a multitude of stakeholders are impacted by civil commitment, and that most times, it's the loudest voice that gets heard. The Commitment to Change Workgroup wants to hear from a wide breadth of people and the broad range of voices. She explained this this session is to hear concerns/ideas from people with lived experience of psychiatric holds.

What do you think is important for us to understand what's working/ not working?

- Patient's experience made her feel unsafe. There are holes in local ER process. They're unequipped for mental health holds. Essentially just in a room for 3 days. Medical professionals are doing the best they can but they're not mental health professionals. They don't understand what medications patient is on and don't have communication with psychiatrist.
- Patient wrote a google review on her experience with a psych hold: https://www.google.com/maps/contrib/103289355056906287292/place/ChIJcQlHcE4JlVQRjc1q5vKA5Qs/@45.5058879,-123.1129705,10z/data=!4m6!1m5!8m4!1e1!2s103289355056906287292!3m1!1e1?entry=ttu
- Was still experiencing symptoms when written. Had interactions with nurses that felt unsafe. Believed to have had PTSD flashback. Not sure whether she experienced an assault in the facility or not. Only one staff member that wanted to help her. She tried to relay info to nurses and doctor that could do intervention but had extremely long wait time while experiencing PTSD flashback. Patient was reprimanded for allowing another patient to put arm around her because having anxiety. Nurse asked if wanted test kit and how to proceed but never received follow up communication, counseling, etc.
- When asked about follow through on report of sexual assault, patient explained that she was so shaken up and she'd talked to police when at hospital. However, once had kit done and turned over those things, struggled with capacity to follow up herself.
- When asked about how the Kit was performed, patient explained that she had concerns. There was limited understanding of what kit entailed. Patient was told that by other patient putting arm around her could affect kit outcome. Feels like if someone would've talked to her, it could've helped guide her through flashback. Generally, just didn't feel supported.

- Other attendee stated that entire mental health system is broken. He believes OSH is in too high demand and patients need the highest level of care from people with the greatest experience and training. However, often times patients are getting help from people with the least amount of training/ skill. Workers have high degree of confidence, but they're doing it poorly because they haven't been well trained.
- Has had the same experiences. People doing best with what they have but not high enough level of standard for what these populations need. We need to catch people upstream. Right now, it's

only happening when in a crisis. Need more highly trained professionals in both OSH and community hospitals.

- Attendee explained that his experiences are real and patients are struggling to navigate what's going on and determine whether it's a shared reality or non-consensus reality. However, there's nobody helping or supporting going through those realities.

Any experience working with peer services? If so, has it been helpful?

- Peers (other people locked up with him) were best resources. Had mostly positive experiences with people specifically certified as peer specialist as well, but get the sense that they're under resourced.
- Staff members that have the most time working with patients have the least amount of training and education. Even when trying to help, they don't know how. Training needs to be increased and peer support utilized more robustly.
- There tend to be a lot of conversations regarding the process leading up to civil commitment. However, there needs to be more conversation around what happens during civil commitment. When people going through this experience, it's very challenging and they need highly skilled people to understand that person is likely not making the best choices or might be making different choices if they were feeling better/life was more manageable. However, they should not be disregarded. Difficult recognizing and setting the two apart. Talking about forensic peer specialist, suggested looking at CASA as a model for creating advocate that could connect with someone immediately when they enter the system. Can have training but able to balance; they can help understand that this isn't a shared reality but still validate the individual's reality.
- From experience, can't always understand or remember what's happening. People are asking all these questions and know info about you which just amplifies the paranoia. Would be helpful to have someone beside you slowing things down and comforting you by asking questions such as:
    - Could we have one question at a time?
    - Do you need a moment?
    - Do you need a drink or to take a break?

Would it be better to put resources towards this? Or bring in third party for advocacy? Should this person be a volunteer, or a new OHA created role that assigns a support person to you?

- Training is needed at all levels, including clinical staff, defense, and DAs. If you don't learn it well, you're going to think you know what you're doing but you're not. Additionally, we still need advocates. Makes a difference having someone holding space with you. If housed with agency and is vetted, bias surfaces, and the staff cannot be used for advocacy purpose. Probably need to create organization to serve this purpose. Independence of the advocate is an important feature of the role.
- Through experience in a previous hospitalization, having third party non-affiliated was extremely helpful. They informed her of rights, went over problems, and validated reasons why she felt unsafe. She was given an opportunity to see where processes work and where they don't. Would've been better if there was someone earlier in the process like while going through intake.

- Both participants agreed that having someone available during hospitalization would be extremely helpful to assist in understanding what's going on the patient doesn't have to keep getting passed on and reiterating their story.
- Participant commented that when doing skill-based learning, people practice first so the risk of getting it wrong is low. Need classroom instruction as well as opportunities to practice with other people learning, then putting it into action.
- It's not helpful for individual to be their own subject matter expert. Can cause them to be labeled as an unreliable narrator. It creates skepticism and causes the next clinician to not trust them. Clinicians don't consider context in which inaccurate statements were made.

- Participant also indicated that socioeconomic status creates different experiences within the civil commitment process. Higher class individuals are able to quickly get supports and find resources while lower class individuals do not receive as much support. Some have even been advised to encourage mental health decline in order to increase severity and dangerousness before someone is willing to step in.

What is your experience with people trying to navigate the system that don't have peers/family that can help them?

- Law enforcement usually gets involved. Only time you get attention is when you're committing crime.
- Experiences with law enforcement has been mostly negative. They come in with the mentality that this person is a threat that needs to be neutralized.

What was different in positive experience with law enforcement?

- Officer just talked to patient who was in a psychotic state. Participant doesn't have a great memory of it but vaguely remembers the officer saying "something bad is happening. What can I do?" Officer provided time to talk and didn't challenge his reality. Officer still never violated his training and maintained safe distance from him. Officer only asked one question at a time and made clear short statements. Officer's tone was neutral; showed genuine concern and curiosity.

Is there a difference when the situation involves potential harm to others?

- In both situations, law enforcement might be reasonable and the only available response. But it comes down to training.
- Other participant explained that she doesn't have experience with law enforcement, but has had welfare checks, and they were also negative experiences. Devolved quickly when officer is speaking in authoritative manner and posture is defensive.
- Highlights if the leadership culture of the organization isn't invested, then training won't help make any shifts.
- Discussed having an option other than hospital or law enforcement. A lot of times if you go to hospital and say you're feeling unsafe, they'd say you're not in enough crisis to help. You're advised to go home and call crisis line or a mental health caseworker.

What are some ideas of other resources?

- Explains that there are a lot of other resources, but it varies based on experience of individual. Not everyone is able to recognize mental health crisis for themselves. Not everyone goes into a crisis state quickly. Therefore, it creates variables for what one can/can't do. Every county should have peer support/advocate/friend resources that create community, so they know what's available when going through any type of experience. Make sure every county has peer run resources.
- Suggests also that it should be staffed by peers. If not at core of mission, they have to go where the money is. These would be specific for mental health focused resources, rather than for substance use disorders.

What other options you think might be helpful when someone in crisis? What else do we need?

- Have lack of therapists and intervention in general. "An ounce of prevention is worth a pound of cures." Why don't we have resources when able to self-identify if something is going wrong? That's the safest time to intervene. Early intervention allows individuals the ability to be set up for success in the long run.

What are your thoughts and experiences around facilities that say no to a person wanting help or placement there?

- Explains that it's a sellers' market. There's so much greater demand than availability. Facilities are able to define what level of acuity drives who gets in. Once they get in, they stay longer than they need to. Keeping the facility full sustains funding. There's no motive to take new untreated patients. It's simpler to treat patients that are calm and articulate, over highly dysregulated individuals.

Do you know if there are any regulations that require acuity-based decision making, and do you think it's feasible?

- Not aware of any regulations. Believes it's feasible but doesn't know that it'll work because have such greater need than capacity to meet needs.
- Trauma informed care and trauma specific trainings have to be central to all of this. Has to be mechanism that monitors and measures whether or not an organization is trauma informed and services are meeting those goals. Right now, facilities get to say they're trauma informed, but not always accurate. There should be formal process to certify trauma informed facilities.

Follow-up comment in email from participant:
As family and friends are often tasked with providing support services to someone experiencing a mental health crisis, it seems reasonable that they should receive support in doing so. I think of the various resources made available to families who provide support to loved ones from Adults and People with Disabilities (APD) such as meal preparation, home cleaning, respite, food stuffs, etc. These have been shown to be significant supports to caregivers and cost effective. It is much less expensive to keep someone in their home or the home of a loved one than in an ER, inpatient hospital stay, facility, or the State Hospital. Moreover, the benefits of helping someone stay connected to their community and natural supports cannot be overstated.