# Improving Psychiatric Residential Treatment Services for BIPOC Youth in Oregon

## **Project Overview**

Oregon offers an array of facility-based residential treatment services, including psychiatric residential treatment services (PRTS), sub-acute psychiatric treatment, acute inpatient psychiatric treatment, secure inpatient psychiatric treatment, and the SAGE residential program for youth with intensive behavioral health support needs. While serving the whole state, the bulk of these services are located in the Greater Portland Area. In recent years (2015-2018), Oregon's PRTS capacity decreased by at least 67 beds (OHA website)— a 50% loss to PRTS which has not been replaced, and it is widely accepted that each of Oregon's residential service options has limited capacity to meet the needs of Oregon's youth overall, let alone the culturally-specific needs of Oregon's BIPOC youth. This said, the demand for intensive support is growing. The need is present to address Oregon's capacity to provide culturally-specific, residential treatment services to BIPOC youth with behavioral health challenges.

What does equity in youth residential services look like—and how do we get there? BIPOC youth who have participated in these services, and their parents/caregivers are the experts, and in the best position to address and answer these questions. They must be the ones driving this discussion and the change effort. To answer these questions, NAMI Multnomah has engaged youth and parents/caregivers of youth who have utilized intensive behavioral health treatment services to inform OHA's future action to improve residential psychiatric treatment services for youth (e.g., PRTS, sub-acute, acute inpatient services). This project focuses on BIPOC youth and their parents/caregivers in the Greater Portland Metro Area.

The graphic below was developed in March 2020, when OHA sponsored a strategic visioning session to "imagine how Oregon could better support children and youth needing the highest levels of care for psychiatric symptoms [and] ensure the highest levels of care for youth psychiatric residential treatment". Our effort builds off of this visioning session, and zooms in on the "actualized equity" piece. Equity must be amplified throughout every component of this vision, and service recipients (BIPOC youth and their families) must be front and center to guide the way.



## Methodology

To do this, our approach contained four steps, to: find, listen, learn and inform.

- To find BIPOC youth (ages 12-25) who have utilized psychiatric residential services, and parents/caregivers of BIPOC youth, whose lived experience can drive discussions about existing service gaps and concerns, leading to recommendations and a plan of action for needed change. To do so, we 1) collaborated with community partner organizations to conduct outreach; 2) developed and distributed a survey; and 3) selected participants for interviews.
- 2. To listen through interviewing diverse BIPOC youth and parents/caregivers of BIPOC youth (who may or may not be BIPOC themselves) about their experiences with the continuum of residential treatment services. To do so, we: 1) developed an interview protocol; 2) interviewed BIPOC youth; 3) interviewed parents and caregivers of BIPOC youth.
- 3. To learn, using two workgroups (one youth, one parents and caregivers) to review interview findings (how BIPOC youth and families experienced different residential treatment services), identify themes, acquire additional perspective, and discuss gaps/disparities resulting from current policies and practices.
- 4. To inform OHA of our findings, which is done in this report, offering detailed examples and general themes of what is and is not working currently, and recommendations for improvement.

All youth and parents/caregivers who participated in interviews and workgroups were compensated for their time.

# **Project Participation**

## Surveys

Two surveys were created and distributed: one for BIPOC youth (currently age 18-25) who utilized psychiatric residential treatment services under the age of 18; and one for parents or caregivers of BIPOC youth who used these services while under the age of 18. Each survey was available in both English and Spanish.

The survey responses received included:

- Parent/Caregiver Survey 28 responses (20 in English, 5 in Spanish, 3 non-usable)
- Youth Survey 6 responses (3 useable, all in English)

## Parent/Caregiver Survey

- The survey comprised a series of questions related to: access to information and services, service delivery, discharge planning, and satisfaction with services.
- The services used by respondents were:
  - Hospital Inpatient Psychiatric (11)

- Sub-Acute Psychiatric (7)
- O Psychiatric Residential Treatment Services (11)
- SAGE Residential Treatment (5)
- Other (8)
- The demographic composition of respondents were:
  - O Age of Child at Time of Service Ranged from 8-18, with most between 12-18 years old.
  - Child's Race/Ethnicity Black/African-American (30%), Hispanic/Latino (30%), White (30%), Other (10%).
- Within the survey responses, parents and caregivers generally noted that it was difficult
  gaining information and access to services; their needs were not always considered or
  centered in child's care planning or service delivery, and families did not always feel that
  the youth was safe after returning home from residential services.

#### **Youth Survey**

• While six total youth took the survey, only 3 of the respondents were over the age of 18 (the minimum age to take the survey). Answers to questions varied between these three participants.

#### Interviews

All youth and parents/caregivers who responded to the survey and met criteria for the project were invited to participate in interviews. Additional youth and parents/caregivers were invited to participate as well. A total of 21 interviews were conducted with both youth and parents. Interviews were 45-90 minutes long.

- Parent/Caregiver Interviews
  - o 15 interviews were conducted
  - It should be noted that the majority of interviews were conducted with white parents/caregivers of BIPOC youth (a combination of biological and adoptive parents).
- Youth Interviews
  - o 6 interviews were conducted with BIPOC youth, ages 12-27, who experienced mental health residential services before they were 18.

## Workgroups

Four workgroups were held, where participants reviewed a compilation of interview findings, identified general themes from the aggregate interview results, and developed recommendations for change/improvement within the service system.

- Workgroups for parents/caregivers and youth were held separately.
- Parent Workgroups:

- 3 total workgroups
  - Total at Workgroup 1: 6 participants
  - Total at Workgroup 2: 8 participants
  - Total at Workgroup 3: 8 participants
- The Parent Workgroups focused on 5 key areas:
  - 1. Access to Residential Treatment Services & Information;
  - 2. Discharge
  - 3. Culturally Specific Services
  - 4. Interactions with Families
  - Therapeutic & Related Services.
     A sixth topic emerged from conversations which was then addressed in the 3rd workgroup: Interaction of Mental Health and Other Service Systems/Needs.
- Each workgroup developed themes from the interview findings, and then formulated recommendations for change within each of the topic areas.
- Youth Workgroup:
  - 1 workgroup with 4 youth participants
  - The Youth Workgroup focused on 5 key areas:
    - 1. Environment
    - 2. Staff
    - 3. Cultural Considerations
    - 4. Respecting Youth
    - 5. Activities, Coping and Treatment
  - The workgroup consisted of a facilitated conversation where the group discussed each category to formulate recommendations for change.

# **Findings - Youth**

Valuable, powerful, and often concerning information was gathered as BIPOC youth detailed their first-hand experiences interacting with Oregon's mental health residential treatment services. Overall, by sharing what did and did not work for them, and their vision for better services, the youth hope for their input to inspire positive change (big and small) for future service recipients. Comments are broken out below into the following categories:

- Therapeutic Environment the physical environment in which youth are supported
- Staffing staff behaviors and interactions with youth
- Cultural Considerations to Support BIPOC Youth race, religion, and other culturallyspecific issues when supporting youth of color
- Respecting Youth recognizing and acknowledging youth voices and needs
- Activities, Coping & Treatment getting the support needed while in treatment to move forward
- Final Thoughts (A Better Future) what youth want from the service experience

Detailed below, youth provide vivid examples of their experiences, concerns, and imaginings of something better. Of special note are descriptions of abuse, staff insensitivities, and perceptions of a system more focused on punishment rather than recovery. This said, they hope their voices, their ideas, the opinions and their experiences will be taken seriously in pursuing better options for all youth, including those identifying as Black, Indigenous, or People of Color.

#### **Youth Notes & Recommendations**

Why are we here? (from Youth Workgroup):

- "Because I believe getting help shouldn't be a bad thing, and it is for some kids."
- "I don't want anyone to go through what I went through. I want youth to get what they need to better themselves."
- "My little sister is in residential. I want it to work for her."
- "If we make it better for youth, people won't have to go through what some of us have gone through."

## Impact on Youth (From Interviews):

- "I have more trauma than ever from being [in residential treatment]. I'll never forget it."
- The tackles and restraints make it hard to heal from your own trauma when people are tackling and kids are screaming.
- "This is important for any real change." People who have experienced this are going to need to tell about what they went through so people know what needs to change.

# **Therapeutic Environment**

- Room size makes you feel caged like a prisoner.
- "There were two big rooms. To get one, you had to be good. If you're suicidal and having big feelings, you lose the room. They'll threaten you with it. I had a very hard week after four good weeks, and they kept saying, 'One more strike and you lose the room.' It was too much pressure. Restriction and consequences aren't really good."
- It was super uncomfortable. It felt like being in prison. To go to the bathroom, I had to ask them to let me. It felt like you were a prisoner. "Even before I knew what prison was, I was in prison."
- Make the food better.
  - o "We're human beings, not animals. There shouldn't be hair in my food. There shouldn't be a fly in my food."
  - "Measuring my cereal is really toxic to everyone who has an eating disorder."
- There weren't many opportunities to do outings, only two to three times per week.

## Recommendations

### What should the environment in residential services be like?

- It should give off a welcoming vibe. I want to be able to feel open and a space where I
  can be honest.
- The space should be bigger, not claustrophobic or like a jail cell. Felt more like prison than like "I'm here and people care about me." Youth stay for a while; it shouldn't be tiny and hard to stay there.
- Improve the beds:
  - I cannot do the hard work during the day if I can barely sleep.
  - O Beds were like bricks. My back hurt in the morning. Please give us beds staff would also be willing to sleep in!
  - Even a college dorm type bed, so we can sleep. Doesn't have to be expensive.

#### • Decoration:

- Ability to add personal decorations and make it more personal.
- O Make the rooms of a healing space more colorful--light green, pink, not blech and bland.
- O Posters and art on walls. Not necessarily childish, but positive and happy!
- O I wouldn't like rainbows that would make me feel like I'm in kindergarten. Be appropriate to our ages in the decoration.
- O Lighting was either dull, like nighttime, or excessively bright. Use pleasing light.

## What would make the space better for supporting youth?

- Have your family there when you first enter the building.
- Having a welcoming committee—of peers and staff member who introduce themselves by name, not just "staff."
- We need to know the staff is there for us, not merely there to do a job.
- Knowing that the staff wants to be there. If you walk in and see the staff on their phones, not welcoming you, or they ignore you on your first night, that does not feel like they are there to support you on your journey to get better.

# **Staffing**

- "They told me I'm struggling with power, but I wasn't the one struggling with power. I picked a place to sit, and they would make me move."
- Staff beating up kids (restraints, holds, tackling kids, throwing a kickball in a kid's face while kid was being restrained).
- "I heard the case manager bashing a youth to another staff. She was rude. If I said hi, she would glare at me."
- "I had to live there. You [staff] get to go home at the end of the day. If you don't want to be here, by all means leave. They seemed grouchy and depressed. There are kids who

- need your help and support. This is not the kind of job where you can wait a year to see if you like it."
- Dragging—"Grabbed us by our hands or wrists to take us outside if we didn't want to go
  outside when we were upset. It didn't always feel safe to go outside. It was scary."
   Made her want to fight.
- "When you did something, they wouldn't talk about your mental health. They would give you a consequence."
- Some staff you could tell they just really didn't care. One staff member was restraining a kid, and another staff member threw a kickball at the kids' face. The other staff saw it, and didn't do anything about it.
- Some kids got restrained. The "shit-stirrers", and the people who kind of gave the intent of attacking people. People going around trying to break things would be put in their rooms.
- "Staff would do a lot of favoritism. Once, every other kid got candy, but I didn't."
- They'd talk in front of kids about the level of care they should be at.
- "The therapist wouldn't let me have family therapy when I asked, because she said I didn't need it because I wasn't going home."

#### Recommendations

- More supervision so peers can't beat each other up. Staff needs to intervene.
- Everybody needs to be held responsible. If someone makes fun of someone else and that person retaliates, both parties should have repercussions (not just the person who retaliates).
- There should be more rules and regulations at residential treatment centers about when it's appropriate to put your hands on someone. Is it really necessary?

### What skills, qualities or characteristics should staff have to better support youth?

- Watch your tone. Speak with more control than the kids can.
- Diffuse situations through mediation, not by shutting people down.
- Staff need to complain less about their jobs. You don't know how it feels to be here 24/7. There needs to be a lot less job dissatisfaction shared with youth.
- Staff get to go home. We don't. Be mindful of youth's situation.
- Stay off your phone and social media while working. Focus on the kids.
- Three staff were on their phones when I first walked in and stayed on, obviously scrolling. Stop! Greet youth who first get there and be mindful that they lost phone privileges. Put your phone in a box like kids do in school.
- Be engaged and care about your job.
- Find words other than "Calm down." It sounds racially biased and doesn't work anyway.
- Be culturally aware and advocate! Never allow one youth to be racist toward another.
- Gain the skills to deescalate a situation through spoken mediation rather than physical intervention.

- Talk to kids about situations that escalate. Listen to youth, talk to witnesses, and try to understand a situation before making a decision about how to respond.
- More staff with counseling skills.
- Teach staff how to respond rather than react.
- Be much more discerning about when to go hands-on.
- More one-on-one interactions with staff to offer a break when there are escalations. Youth get physical when they feel defensive. Help us feel comfortable asking for advice.
- Learn from family about how youth can be supported. Welcome their advice.
- Learn from youth about how they can be supported. Build a bond with youth so there can be some trust for when the big moments arrive.
- More opportunity to develop one-on-one relationships with staff who can become a youth's go-to instead of feeling as if escalating is the only choice. Maybe 3-4 staff per youth.
- Cooks need hair nets. Hair in food-often!

# **Cultural Considerations to Better Support BIPOC Youth**

## Highlights from Interviews

- Staff ignored blatant racist things happening to me and other youth. They saw it, but didn't say or do anything about it.
- Almost all the staff were white, except maybe three of them. "For the first month or so I was the only kid who was Black there until another kid showed up...one time there were some people making fun of us and we pretty much unified for us, like this wasn't okay."
   The staff took a stance like we won't treat you any different, but they were ignoring what was happening. The staff NEVER addressed this.
- They told a girl she wasn't allowed to speak Spanish.
- "Did not let us celebrate holidays as a family. We got one hour for my birthday."
- Had braids and I needed to have a cap if I had to shower daily, but I didn't get that.
   Couldn't pull my hair back, either. I understand that I'm a suicide risk. Just knock on the door more frequently. You're telling me I have to shower every day then not allowing me to have what I need.
- Staff restrained youth for lashing out after another youth's racial slur, but did nothing to youth making the slur.

## Recommendations

- More diversity of staff:
  - Need more BIPOC people on staff. Advertise outside white communities/spaces for open positions. There need to be more providers of color, and more cultural responsiveness.
  - More diverse staff so youth can relate better to staff.

- Advertise more broadly to find diverse staff. Problem-solve hiring to overcome barriers to finding diverse staff.
- Religiously diverse staff is important.
- Give me a Black advocate. Give us people who look like us and understand our struggles.
- Keep the family in the loop. Listen to the parents and family; they know a lot.
- Respect different religions and cultures. Let people do what they need to do to express their religions and cultures. Ask questions to find out what their practices are.
- Make time and effort to address dietary restrictions. Do not make judgements about people's diets.
- If I have braids, let me bring my hair cap. Also my own soap and lotion. I have a different hair and skin type.

# **Respecting Youth**

- No privacy in shower. Should have had a curtain.
- (Not knowing what to expect.) "They would trick you a lot."
- "Not knowing what was going to happen next. Not having the control that a person has
  in their life, not knowing the next step. I think that was probably the worst part of
  everything."
- Did not treat us like humans.
- They did room clears by ripping things off the walls and damaging the only property kids had.
- They were not friendly at all.
- Didn't help me understand what was happening in a way I could understand
- "They forgot that we had ears." [And would talk about her in front of other staff.]
- Staff pushed what they thought was better, not necessarily in line with what youth wanted, or understanding how he felt. "They were so quick to push stuff, not ask you what you want."
- Communication with staff got the message that "I didn't know how to communicate."

  People didn't try to help me communicate."
- Don't punish for mental health.
- "I would try to talk to the therapist, and she would say, "No, we can't talk about that. I couldn't talk about things in the milieu, but this is therapy. I need to talk about it."
- "They told me when I could shower and when I could eat. I like to start my day with a shower. They said no, you're a pm shower. And I woke up before anyone else. The showers were open. I said, "Why?" [Never got an answer.]
- Staff did not explain what they were doing and why they were doing it. Example: forcing her to change into a gown without checking in or hearing her needs. Doctors doing exams without asking me or telling her what was happening. Being held down on the bed several times.

## Recommendations

- Treat kids as allies in getting healing, not as enemies.
- Communication:
  - O Kids need to be heard and need to be part of the process. Explain to kids what's going to happen.
  - O Listen to kids. They know their minds more than anyone else knows them. If they show you something, you need to listen to them and let them in on the plan.
  - Sit down and explain things instead of talking at kids. Make interactions feel personal and connected with kids. "Being personal with the person can go so far."
- Let me decide when I want to shower and change my clothes based on my needs. Kids are trying to stay alive. Don't worry so much about their hygiene.
- Staff wanting to do their jobs makes a big difference for kids.
- "I would feel uncomfortable and not want to go in my room but they would force me. They would tie me up and force me into my room. Literally tie me up."
- Not as much physical restraint for little kids. Little kids don't know and understand what is happening.
- Consistency in how the staff treat youth all staff should have the same rules for youth, instead of youth having to figure out what to do for what staff to be on "good behavior".
- Wish for more mentorship that helped him feel comfortable. Getting to know that one
  person and building trust. Someone who can help get you into it and pay attention to it.
  Instead of just being told what to do.

### What helps youth feel respected by staff?

- It's our job to trust the adults that are trying to help us. Do the things that help us trust.
- Try not to get physical with us.
- Take youth seriously. If a staff member makes them uncomfortable, do not put them alone in a room.
- Keep us in the loop about our treatment. Help me understand what's happening. Tell
  me about my meds. I shouldn't have to dig for information. No one told me my
  diagnosis.
- Talk to us, not only about us. Keep us—not only our parents—updated.
- Listen when I tell you what I need. I will know they are listening when they help find a middle ground rather than insisting on their way.
- Show kindness, be warmhearted.
- Increase sensitivity and empathy. Perhaps offer classes in sensitivity to staff.
- Don't make fun of us for anything.
- Use a calm, respectful tone.
- Ask how we're doing throughout the day.

# Activities, Coping & Treatment

## Highlights from Interviews:

### Coping

- Felt hopeless. Couldn't let out big feelings.
- Not a quick learner and felt he was being pushed, especially at the end.
- They wouldn't let me do stuff that I needed to help me (like taking a shower at facility). "It felt like I was being punished, when I was there for help."
- When she was having a panic attack, they would raise their voices, and it didn't help. Never asked what would help me through a panic attack.
- Felt like a lot of talking all the time. Felt like she needed to hide away sometimes and escape
- "How is locking me into a tiny room going to help me feel more calm? We are human beings, too. Once in the ER, I was in a room for physical health, and it was bigger and so much better."
- When someone says they've been sexually abused, especially if it's more than one girl, believe them. I was scared to tell DHS and said nothing happened. I'm still scared to say anything, because I'll get blamed or retaliated against. I just don't want to say anything now, but it's in my mind a lot.
- Staff were not supportive at all. "If I said I need help, they would tell me to calm down for ten minutes first before I could have a support call. If I could calm myself down, I would."
- "They put you in seclusion when you were suicidal. You couldn't have any art supplies, nothing, and the person who was with you wouldn't talk or say anything when you cried. When you tried to talk to them, they would stay silent. It made you more suicidal. Everyone said so."

### Medication (from interviews):

- Medication: "I felt drugged as a little kid. My childhood was robbed because I was on medication that made me feel like a zombie."
- Not as much medication for kids, and trying to find other ways to work with kids
- Medication management don't remember the doctors or anything else
- When she wandered out of room to look at the sun, she was told she'd be given a sedative unless she went back to her room. No empathy.

## Recommendations

### What kind of activities are useful?

 Help kids feel comfortable in ways that are tied to what they need. Showers to help them calm down when they need it, the kind of music they like. Help them feel comfortable.

- Help us develop more coping skills.
- Have more group activities to help youth bond. It's more welcoming when we know each other.
- Take youth on outings outside of treatment center.
- Offer youth computer time and video games.
- Being physical activities. Basketball, running, volleyball, dance.
- More outside time.
- More time, space and encouragement for reading. Offer a book club. Quiet group reading time. Someone reading aloud.
- Bigger variety of available books. Individual time to read. Allow us to bring books from home.

## What would be useful to youth in therapy?

- Therapy at least once a week. Someone you can really talk to.
- Therapy dogs, rabbits, rats. Any therapy animal.
- Fidgets, stress balls etc.
- Allow youth to take a break or excuse themselves from therapy without losing privileges.
- Let us set goals in therapy.

# **Final Thoughts**

### What could youth learn or get out of their time in residential services?

- A better perspective on life.
- A concrete set of next steps. A plan. Families need all the answers to their questions and a list of resources so kids don't end up back in care.
- Get into the real world before discharge to get used to life again and build confidence in our ability to deal with it.
- Know that there is something better out there. There is more than just going from place to place. Learn to accept the help and coping skills that are learned in residential and take them into life.

# Findings - Parents & Caregivers

Parents and Caregivers of BIPOC youth shared meaningful critique of their families' experiences with Oregon's residential mental health treatment services. Equally passionate, parents detail the struggles to understand and access residential treatment, get the appropriate cultural and therapeutic supports for their child, have a voice that is valued in the treatment process, and emerge with a discharge plan that will support a successful transition home. Below, broken out into the following categories, families share their experiences with a system that is crisis-driven and struggles to value the family as equal partners in the treatment process:

- Access to Residential Treatment timely information and access to an array of residential treatment service options
- Discharge Planning planning for next steps after treatment that are realistic and support both the youth and family for a successful discharge
- Culturally Specific Services systems to support youth of all races, religions, and cultural backgrounds and identities
- Interactions with Families communication with and inclusion of parents and caregivers in the treatment plan
- Therapeutic & Related Services the mental health services and supports available to youth and their families
- Intersection of Mental Health & Other Systems/Needs considerations for inter-system collaboration and learning

Combining their own experiences with those of other families, parents of BIPOC youth identified multiple common themes or issues requiring attention of program administrators and policy makers. As problem-solvers, they then offer concrete recommendations for service system improvements.

# **Parent/Caregiver Notes & Recommendations**

## **Impact Statements**

- "It's not our kids who make parents feel like giving up; it's the system."
- "The system of getting any level of support is messed up."
- "Hope and pray someone will listen to how damaging the current system is to children, parents and caregivers. We are putting adults into the world who can't support their mental health."
- "Ask! Kids don't have the words. Giving them a voice could cut down on behavior problems."
- Educate youth and families about the importance of their mental health self-care. Educate them about their mental health diagnosis.
- "You have to take what [services] you can get whether it's good or bad, because at least it's not nothing."
- "Absolutely not enough help for the parents. We need to partner better, but it needs to be a good partnership."
- "Show [youth] who they are matters. They lose everything when they go into care. They need to keep more pieces of their identity."

## **Access to Residential Treatment**

## Highlights from Interviews

- "You have to know the secret password to get into these places."
- "Criteria should not be our kids leaving marks on someone or attempting suicide before they get residential help when they need it."
- "Get them in before they leave marks on someone else. Get them in before they have an active plan to kill us, not just threats. Get them in before they try to commit suicide actively."
- "[My child] needed to be in residential a lot sooner...The way we got to [provider] was all on my own."
- "We were told we had to play the game to get [my child] in there [residential]. It should not be a game to get into residential. These kids need help long before they get into [residential treatment]."
- "Most of the time I felt like I had to constantly tell the story of how evil [my child] was or we wouldn't get help."

### Themes

- Lack of readily available and reliable information about treatment and options
- Limited choice of providers and programs
- Crisis oriented not gaining access until point of crisis, with no support for prevention
- Access through Emergency Department, crisis response services unable to support
- Problems with intake process
- Lack of help for parents, lack of integration into process

## Recommendations to Improve the System

#### Access:

- More programs and better access. There should be more beds and more locations available with shorter waiting times to gain access to residential treatment.
- De-mystify how to access services. Criteria for access to treatment needs to be standardized and transparently communicated.
- More residential treatment with dual diagnosis (mental health and developmental disabilities) focuses. Follow IDD model for mental/behavioral health issues.
- o Families should be able to gain access to support prior to crisis point (suicidal ideation, self-harm, harm or threat to others).
- o Families should be able to gain access to residential treatment programs and meaningful support currently accessible only through DHS involvement.
- Create multiple paths to access services.
- o Better crisis response that comes to the home without police involvement.

## Support for families:

- There should be parent mentors/peer support partners at every intake who are there to support parents through the process.
- Culturally specific peer support should be available early in the process.
- Provide meaningful support for exhausted parents so they can support their youth.
- o Provide family-friendly information from the start of treatment.
- Have culturally specific workers on site at every point of contact, starting from intake.

#### Involve families:

- Listen to and respect parents, and center their concerns from the start of intake.
   Take their experience and knowledge of the youth's history seriously and integrate this from the beginning of treatment.
- Gathering information should not be "fault finding" within the family.

## Transparency:

- Hospitals and residential treatment facilities should be providing realistic and accurate information to parents from the beginning.
- O Be open, honest, and transparent with families.
- Provide clear and transparent information about families' options so they can be informed and make choices.

# **Discharge Planning**

## Highlights from Interviews

- "Discharging [my child] suddenly with no plan when the insurance was up was criminal...It was very traumatizing."
- "[Provider] emergency discharged with zero plan."
- "Do not discharge early without a solid safety plan. Do not."
- "Where I feel like they screwed us over was not having a plan for long-term...Patients are pushed out before they are ready."
- "The ER doc said that our kid was too unpredictable to admit and needed acute care; when acute care turned [my child] down, the hospital told us we'd be fine and insisted on discharging right away. They seemed not to care at all when we said we definitely were not fine."

#### Themes

- Need for written discharge/transition/safety plan
- Support to access/set-up community supports
- Make sure plan centers youth and family needs and is realistic to their individual situation.
- Follow-up after discharge.

- Gaps in service zero medication management between discharge and next provider.
- Discharge planning is rushed and insufficient.

## Recommendations to Improve the System

- Discharge planning general
  - O Discharge plans should be individualized, <u>culturally responsive and realistic</u> in order to respond to family's needs and capacity.
  - A child should never be discharged without a viable safety plan.
  - O Discharge planning should be a continuous process while in treatment—rather than waiting until the end of treatment.
  - Center culturally specific discharge planning, including having culturally specific support at discharge planning sessions.

### Care Planning

- Include recommendations/resources for community support, including culturally responsive support for families.
- Close gaps in service between residential treatment and next steps: warm handoffs prior to discharge to avoid lapse in care, particularly psychiatric care.
- O Transition and discharge planning should include long-term care planning.

### Support after discharge

- O After transitioning out, have someone from the agency check in to see how things are going, for continuity for kids. They need to know someone cares.
- o Implement follow-up by provider to keep plan a working document that responds to family's real needs.
- Immediate and continuous support for family and youth after discharge.
- O Involve youth and family peer support in the discharge process, and continue their involvement to support the transition home.

### Center youth and family needs

- O Work with the youth and family to facilitate a successful discharge.
- O Provide youth and families with information about their options and ensure they understand what to expect in order to make choices.
- O Safety plans need to work for parents and caregivers. It must be realistic and doable, and parent/caregiver needs must be considered.
- Work with the family to facilitate a more successful discharge.
- o Ensure the family is informed with due notice before discharge.
- Be transparent with families about rationale and criteria for discharge.
- Provide parents and family guidance on next steps after discharge.

# **Culturally Specific Services**

- "When you are consistently treated poorly and your child is a child of color, it is hard not
  to think that race might be a part of it. That's how I would say we were consistently
  treated poorly. I thought race could be a factor underneath all of it. Whether it was or
  not, I don't know."
- Youth told parent: "When a white boy does it, he gets walked to his room. I get put in seclusion."
- [Translated] "Sometimes people are short when they discover that I do not speak English."
- One parent who is white and bilingual in English and Spanish was compelled to facilitate translating for other parent, who is Latino and spoke Spanish. Created barriers between two sides of the family by forcing them to ignore cultural boundaries.
- One parent, who is white, had access to son through visits. Other parent, who is Latino and did not speak English, had a very difficult time scheduling visits. White parent had to advocate on Latino parent's behalf to be able to see youth.
- They called hair grease "contraband," because it wasn't on their list of acceptable items.
   "[My child] needed [hair grease] and lotion...I had to go over everyone's head to bring the hair grease."
- Often youth wouldn't eat: "They fixed white people's food."
- Neuro-divergent black and dark kids often misdiagnosed.
- "They behaved blindly...to racial differences."
- Felt trepidation about telling agency about concerns. Fear of being accused of "playing the race card" and repercussions. "There are certain things I can't do, because they might take it out on my kid."
- "Black people are very keen about what is going on. Is my kid getting different treatment than anyone else? You've got this history of abuse. You leave your kid in the care of these people. And you wonder what is happening...As an African American, our experience is that we've been abused and experimented on."
- "Ask about culture and what would make the client feel more nurtured...What makes you sleep better? What kind of food do you like?"
- "My child would be better off [working] with a Black person."
- For African-American kids, the question "If this isn't working for you, what will?" Is very seldom asked.

## Themes

- Lack of diversity across staff; little to no Black staff (all positions, from administration to treatment team). Need for more culturally specific staff.
- Limited cultural awareness: not asking questions to support individual youth and families with needs such as hair care, skin care, hygiene, food, family traditions, faith considerations, holidays, etc. Particularly impactful for Black youth.
- Staff not addressing racism against BIPOC youth by other youth and staff.
- Black youth suffering more severe punishments for breaking the rules, unfair treatment and discrimination.
- Youth of Color are more likely to be labeled "behavioral", and directed outside of the mental health system to the juvenile justice system.
- Language barriers for families who do not speak English or where English is not their primary language: not enough support or information in native/preferred languages, less engagement in supporting families when a language barrier is present, families treated differently, use of family members to interpret (including youth), families who don't speak English having less access to seeing their children.
- Staff sometimes have lowered expectations for BIPOC youth.

## Recommendations to Improve the System

- Culturally appropriate support
  - O Ask about family's and youth's culture, identities, and cultural needs. Find out what would make youth feel more nurtured, taking cultural considerations into account.
  - O Support youth by appreciating and nurturing cultural identity. Finding out who a kid is as the first step to better supporting and accommodating their needs.
  - O Play different kinds of music, attuning to what might be relaxing for different kids based on what they are used to.
  - More bilingual staff are needed in residential treatment facilities.
  - Ready access to translated materials and interpretation services for all families and youth whose preferred language is not English.
- Center kids' needs
  - O Show kids who they are matters. "They lose everything when they go into care. They need to keep more pieces of their identity."
  - O Kids need a voice in treatment at every stage. Ask them: "If this isn't working for you, what will work for you?" For African American kids, this is very seldom asked.
  - When something isn't working for a kid, ask and help them articulate what they need.
- Consider context of racism and historical trauma
  - Remember that Black clients have experienced discrimination within medical systems. "Black people are very keen about what is going on. Is my kid getting different treatment than anyone else? You've got this history of abuse. You leave

- your kid in the care of these people. And you wonder what is happening." "As an African American, our experience is that we've been abused and experimented on."
- O Consider that neuro-divergent Black kids and kids of color are often misdiagnosed, and take this into account when diagnosing and treating.

#### Staff

- Residential treatment centers need to hire more diverse staff, particularly more
   Black providers. Staff should be more reflective of the populations served, across all positions (from administration to all aspects of treatment team and management).
- O Staff needs to be trauma informed, including understanding and awareness of impact for youth of systemic oppression and traumas.
- Provide more education and training for staff in cultural humility and personal biases.
- Create and implement a protocol to respond to racism by staff and other youth. Protocol must include an element of accountability for adhering to it.
- More Black staff available to work with Black kids.
- O More culturally-specific staff available to work with all youth and families.

## Peer support

- Hire diverse staff with lived experience in mental health systems to support youth.
- Provide family peer support with lived experience who know how to navigate systems alongside families.

## **Interactions with Families**

- "Families need to be able to share their experiences openly and honestly without worrying there will be repercussions if they need services again."
- "Improve communication between services and parents. Email, phone call. They never once asked me what works for my child."
- "Communication was one-way: Me to them."
- "We were never involved in talking about a plan. We were the recipients of the information."
- "I would get conflicting answers from everyone."
- "They hear you but they don't listen. They do things their own way anyway."
- "I didn't feel heard until I had a family partner."
- "We're looking for our families to be functional, and I think that's what they [the facility] is missing. They kept saying we can't fix her, we can't fix her. I'm not looking for you to fix her. I want our family to be functional, because typical life is possible."
- "Everything seems siloed. There needs to be some attempt from people within the system to show they are working with us. We're not on opposing teams, and that's what I felt a lot. We were competing teams as opposed to working together to try to achieve something."

- "[They] responded to concern about lack of family participation by saying they didn't
  work with families much as it wasn't their model. They said they work with the
  individual, not the family, but this individual had a family."
- "No one acknowledged the impact of youth's behavior on [the family]. We need some
  recognition that the child does not exist in isolation. They are in a family unit. There
  needs to be support for the child. Address the medical component for the child and the
  therapeutic component for the whole family."
- "Black people are leery of even taking our kids into mental health care. Explain to the parent what you're doing. Your child has [this diagnosis]. This is what it looks like."
- "How can we build a system where they can walk parents through this [care]?"
- "Each time we went somewhere, they tried to reinvent the wheel. They didn't listen to our experiences. They thought they knew what would work. They didn't take the years of therapeutic notes. The first few months were wasted because they'd make [my child] prove the issues all over again."
- "The social workers and doctors have no idea how demeaning it is to be told everything is fine when parents know emphatically it is not. Just tell the truth. Don't tell us we'll be 'fine' or that you have good news when the 'news' is simply that the system is broken."

### Themes

- Inconsistent collaboration between provider and parents.
- Not providing enough info to families about treatment.
- Lack of seeking or integrating information from families into treatment.
- Not asking about/understanding or centering family goals in treatment.
- Blaming parents for issues youth is dealing with.
- Treating parents as adversaries.
- Lying to parents (insurance coverage, access to other services, suggesting services do not exist when they do, on waitlist for services, youth is "doing fine").
- Lack of education and support for parents.
- Discrimination and different treatment for some families.
- Access to seeing and communicating with youth was varied for different families in different settings and barriers to being in person (i.e. public transportation).
- Services too siloed.

## Recommendations to Improve the System

- Collaboration
  - Treat families as allies and collaborate with them in all aspects of care treatment planning, service delivery, discharge planning.
  - Acknowledge parents/families as equal partners in the treatment process. Consider parents as an integral part of the team.
  - "The whole family is involved. It's not just about the person who is ill."
  - O Take seriously what parents know about their own children. Use parents as a valuable resource to check about behavior patterns, medication effectiveness,

history of treatments and approaches tried. Use parent input and integrate it while developing a treatment plan during residential treatment and beyond.

- Open lines of communication: Listen to parents
  - Work with parents to establish an agreed-upon communication plan (method, frequency, content, etc.) that works for parents and providers; remain consistent with this plan throughout treatment.
  - Improve communication between provider and parent in terms of medication management.
  - Open space for families to share experiences and feedback without concerns for future repercussions. "Families need to be able to share their experiences openly and honestly without worrying there will be repercussions if they need services again."
  - O Be transparent with parents and focus on improving/building relationships with them
  - O Speak to the parents, not just the youth. Sometimes this should be someone speaking with parents separately, without child present.

#### Access to information

- O Make more information and education available for families. Explain and help them understand treatment (particularly related to medication), and help them understand needs and make decisions regarding their children's care.
- o "How can we build a system where they can walk parents through this [care]?"
- Facilitate better access to medical/mental health records.
- "Explain medication changes to parent. What are we looking for? Black people are leery of even taking our kids into mental health care. Explain to the parent what you're doing. [For example] Your child has ADHD. This is what it looks like."
- Support for parents
  - Provide more support to caregivers who are putting so much into supporting youth.
  - Parents need family support specialists to help them articulate their needs and get them met.

# Therapeutic & Related Services

- "When you walked in [to treatment facility], it felt very prison-like." "Not a healing environment."
- "From what I noticed, it seemed staff aren't able to say what's not working or to air any
  grievances. I noticed there's a huge amount of turnover. It seems easier just to move
  facilities. Nobody tried to improve or fix what's not working. They just move to another
  place."

- "Staff would escalate [youth] while we were on the phone. Some floor staff were thoughtful and communicated well; others were immediately punitive in their communications."
- Their only advice was "Keep [youth] on her drugs."
- When youth was identified as a gang member, there was an automatic assumption of being a "bad kid."
- They treated behaviors, not mental health.
- Lots of punitive consequences and isolation.
- Providers/staff were not cautious about youth's triggers despite warnings and disclosures.
- Youth was given medications prior to receiving an accurate diagnosis that made them much worse.
- "Doctors would say I'm sorry, your [child] is saying [they are] ok so there is nothing more we can do" despite self-harm and evidence of malnutrition.
- "I had an 'aha!' moment when they diagnosed her...these are people who do not know my child who are deciding what to do about my child's future."
- They were unwilling to honor previous psych evaluations and diagnoses by people who knew her better and longer.
- "They had nothing but their therapeutic model, seclusion and restraint."
- Staff said, "We look at this as an opportunity for parents to get respite...That's [respite], not what I wanted. I wanted a diagnosis and a plan."
- Youth traumatized and still vigilant about cameras and loss of privacy.
- "Incorporate more individualized plans...[that are] therapeutic around what works for that kid, so they can feel comfortable in their own skin. That's a huge piece of anyone's mental health."

## Outcomes for Residential Treatment for Youth

- Youth are more able to self-regulate and use self-care skills.
- Better able to use daily life skills. Support youth in achieving independence in daily living.
- Youth are better educated regarding their own mental health and related needs (medication). Motivate youth to continue supporting their own mental health (via positive supports and resources).
- Youth mental health diagnoses are destigmatized. Youth can develop a strong selfimage beyond a diagnosis. Youth are not pathologized or infantilized. Treat youth as individuals rather than a collection of symptoms.
- Youth develop autonomy in all areas, including accessing future services.
- Youth are aware of and access positive peer supports, community supports, family supports. Emphasize peer supports, including 24/7 access to peer supports.
- Youth learn to advocate for themselves while in residential so they will be more able to self-advocate after discharge.

- Youth will learn to use Collaborative Problem Solving and Interpersonal Relationship skills.
- Youth voice is acknowledged and respected as part of treatment process.
- Youth establish more social supports while in care to better facilitate accessing social supports after discharge.
- Youth are offered opportunities to use coping skills/tools while in treatment for better outcomes after discharge.

## Recommendations to Improve the System

- Systemic Changes
  - Develop transparent mechanisms for quality assurance that prioritizes what works for families and youth and what doesn't. Create an ongoing learning environment using feedback from families and youth.
  - Make facilities and environment conducive to healing warm, welcoming homes for children and youth to receive treatment in.
  - O Treat youth mental health barriers, not just behaviors.
  - Expand crisis-based programs like the Crisis and Transition Services (CATS)
     program to meet needs statewide and support youth and families by preventing long-term residential treatments.
- Support youth in developing coping and other skills
  - Offer youth opportunities to use coping skills/tools while in treatment for better outcomes after discharge.
  - O Support youth in asking for help to co-regulate. Simultaneously support staff in learning how to respond to youth's needs and attempt to regulate.
  - Support youth in practicing daily living skills and responsibility.

## Staff

- Staff should be more thoroughly trained in: de-escalation, co-regulation with kids, culturally-responsive support for youth and families, awareness of their own biases, recognizing and responding to verbal/nonverbal communication, implementing trauma-informed care, and Collaborative Problem Solving.
- O Treatment centers should support staff in growth and development, particularly in soliciting and implementing feedback and finding fresh ways to support youth in skill-building.
- Staff should help youth feel cared for (not just in "treatment") while in residential treatment facilities.
- Education & Empowerment
  - Educate youth on their own mental health diagnoses, potential needs, means to self-care, and medication. Motivate youth to continue supporting their own mental health (via positive supports and resources). Support youth in connecting to culturally responsive services and peer/family support in their communities.

- O Support youth in participating in their own treatment, finding words to express themselves. Teach youth to advocate for themselves while in residential so they will be more able to advocate after discharge.
- Help youth develop autonomy in all areas, including accessing future services.
- Youth voice should be acknowledged and respected as part of the treatment process.
- O Youth should be taught to use Collaborative Problem Solving and Interpersonal Relationship skills.
- O Help youth be aware of and access positive peer supports, community supports, family supports. Emphasize peer supports, including 24/7 peer supports.

## Support

- O Support family in establishing social supports while in care to better facilitate accessing these supports after discharge.
- O View youth as individuals to be supported, rather than seeing the behaviors to be addressed. Particularly important for BIPOC and LGBTQIA+ youth.
- O Incorporate more individualized plans. Be responsive to individual mental health triggers/activations, and base treatment around what works for each kid so they can feel more supported and comfortable.
- Practice trauma-informed care in all aspects of treatment. Address traumatic impact of being in residential services with youth and families.
- o Provide peer support for youth with lived experience they can relate to.

#### Medications

 The practice of over medicating kids to keep them "manageable" is not ok. It is a widespread practice known as chemical restraints and must be globally addressed.

# Intersection of Mental Health & Other Systems/Needs

What does OHA need to hear about the intersection of Mental Health and other support needs families have?

- BIPOC youth are often misdiagnosed; DD are missed or diagnosed as ODD. Result is that youth are disproportionately placed in higher-level residential services, rather than receiving appropriate outpatient services.
- Make resources accessible to youth and families across mental health and DDS. Educate
  case managers to be a liaison across multiple services for families. DDS works much
  better than mental health care for youth and families. Make mental health care services
  work as well as DDS.
- Accountability. Train case managers who are knowledgeable across systems. Experience and training is key. Access to these skilled case managers is critical.
- Transparency in all regards, including how to access services.

- Improve community mental health supports and access to same for BIPOC youth in an
  effort to avoid the trauma of residential services, if possible. Act before the point of
  crisis.
- Create a new system to facilitate communication between mental health and DDS services.
- Model mental health systems after intellectual/developmental disabilities support system to facilitate successful discharge with reduced need for return to residential services. Trained and county-funded PSWs. Respite. Similar supports for individuals and caregivers requiring mental health services.

### Conclusion

Throughout all the components of this project, participants have been clear in their assessment of mental health residential treatment services: there are elements that must change in order to better support BIPOC youth and their families. The feedback and issues found in residential treatment services varied widely, emerging into two larger camps of feedback:

First is that feedback which should be taken into consideration in order to make services better and more supportive of youth and their families. Both youth and their families consistently shared experiences of having minimal voice in their own treatment and service – from the point of entry into residential services through discharge and aftercare support. Interactions with staff often did not value their voice and experience as experts in their own lives. Cultural considerations were often not asked about or taken into account.

The second camp of feedback is the revealing of experiences that violate the fundamental rights, safety, and well-being of youth in care. These experiences range from descriptions of forcefulness, coercion, and deep-seated insensitivity of providers – and speaks to systemic abuse that is experienced by children and youth across residential treatment programs. Children and youth left residential treatment centers traumatized. Black youth were punished more harshly and drastically than white youth. Youth experienced unlawful and aggressive restraints that left bruises, and sexual assault while in care. Parents who did not speak English couldn't always access visiting their children.

Of further concern, many youth and parents expressed not having a mechanism to be heard and/or to convey feedback about their experiences with residential treatment centers. This project was the only opportunity some youth and families we spoke with have ever had to provide feedback about their experiences in mental health systems. This is a critical component that must be integrated into treatment provision, and in a way that truly centers and values family and youth voices and needs. Feedback must be solicited in a way that supports families in feeling safe from retaliation or other negative responses. Accountability measures should be in place to support providers in responding to and integrating feedback received in order to work toward continual improvements. Carefully executed collaborative processes and feedback solicitation could be instrumental in supporting treatment providers in designing and improving

youth- and family-centered services that are able to offer culturally specific and responsive supports. Given the emphasis placed on the importance of equity-driven treatment and support, it is critical to develop and implement mechanisms for feedback from BIPOC youth and their families.

Overall, youth and families remain optimistic for a service system that can improve and support better outcomes for their future and the future of others. This starts by listening and learning from their experiences.