Racial Disparities in Behavioral Health Care Grant

FINAL REPORT

Racial Disparities in Behavioral Healthcare Project

WOC

WOMEN OF COLORS

1000 TUSCOLA STREET, SAGINAW MI 48607
(989) 737-9286
WWW.WOMENOFCOLORS.ORG

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INTRODUCTION

It is well documented in the research that racial and ethnic disparities in behavioral health care persist. The Affordable Care Act increased access to behavioral health care, but many reform initiatives fall short when it comes to considering the unique experiences of economically disadvantaged racial/ethnic minorities. "According to the *2014 National Healthcare Quality and Disparities Report*, racial/ethnic disparities in access to treatment for mental health and substance use disorders changed little between 2008 and 2012 (p. 991.)"[1] Disparities in care can lead to devastating outcomes including excess morbidity for racial/ethnic minorities. Given the belief that access to care and high-quality interventions can improve the course of behavioral health conditions, the primary goal of this community-based participatory discovery process is to identify barriers to equitable behavioral health care for African American residents in Saginaw County. Findings will be used to make community-informed recommendations for how to reduce access and follow-up care disparities.

[1] Removing Obstacles to Eliminating Racial and Ethnic Disparities in Behavioral Health Care, Health Affairs 35, NO. 6 (2016): 991–999 ©2016 Project HOPE—The People-to-People Health Foundation, Inc.

SIGNIFICANCE OF THE PROBLEM

Research asserts that disparities in access to behavioral health care are an outgrowth of multi-level systems failures. These systemic breaches occur at the macro-level (the larger health policy level), meso-level (interactions between health organizations, lay sectors, and communities), and micro-level (interactions between provider/caregiver, and client). At the macro-level, low Medicaid reimbursement payments may limit options for care. At the meso-level, minority communities' lack of trust behavioral health treatments may cause the deprioritization of care over other more pressing matters. Finally, at the micro-level, limited support and resources for providers to adopt evidence-based practices can lead to poor-quality care, since under-funded health care systems are the least likely to implement new treatments. When compared to the dominant white population, racial/ethnic minority populations are more often affected by discrimination, racism, and marginalization. These forces affect their interactions with clinicians and health care institutions and lead to reluctance to follow through with behavioral health treatment and then subsequently disparate behavioral health outcomes.

BACKGROUND

Women of Colors was selected to facilitate a community-led discovery process designed to learn about barriers which may exist in Saginaw County that impede equitable access to high-quality behavioral health care for African-Americans. This work was accomplished through a series of facilitated structured community conversations, interviews, listening sessions, and a county-wide survey distribution. It is important to underscore the need of grassroots participation in coming up with effective solutions to identify disparities and barriers.

ADVISORY COMMITTEE AND KEY STAKEHOLDERS

Women of Colors enlisted a diverse Grant Advisory Committee to assist with the implementation of the discovery process.

Our strategic effort also included a continuation of key collaborative partnerships forged with various community-based organizations and institutions throughout Saginaw County. Ultimately the strength of these partnerships is a core factor that enabled us to lead the community to uncover barriers that result in behavioral healthcare service disparities. A critical aspect of the development of the proposed strategic plan was the inclusion of input from three specific segments of the community; behavioral healthcare service providers/practitioners, behavioral healthcare clients and other community leaders and partners who either advocate for minority and socio-economically depressed individuals or have the direct ability to influence critical decision-makers.

Our key collaborative partners are: Saginaw County Mental Health Authority, Saginaw County Public Health Department, City of Saginaw, Saginaw Police Department, Saginaw County Sheriff, Saginaw Public Schools, Saginaw Intermediate School District, NAACP Saginaw Branch, Saginaw County Prevention Coalition, TRICAP, PEER 360, Child Abuse and Neglect Council, Great Lakes Bay Health Center, HIV/AIDS Task Force, Family Against Narcotics, Saginaw Valley State University, Solutions for Behavioral Health, and the Saginaw Behavior Health Action Group.

Many of the organizations identified here have an established working relationship that comes from their membership in the Saginaw Prevention Coalition whose purpose is to decrease substance use disorder including the reduction of underage alcohol and marijuana use. WOC invited all members of the Prevention Coalition to be a central part of our discovery process. The organizational contributors listed here are, in many instances, in direct contact with behavioral healthcare clients and are able to either assess the ongoing effectiveness of service delivery efforts or aid in implementing direct actions to change the course of behavioral healthcare services. They are direct providers and were able to recruit clients to participate in interviews or listening sessions.

SCOPE OF THE DISCOVERY PROCESS

This community-based participatory discovery project allowed community-based organizations to gather local information to uncover barriers specific to African Americans to equitable behavioral health care services. Michigan Health Endowment Fund funding allowed Women of Colors to lead a one-year discovery and planning process in Saginaw County. The scope of the discovery process was limited to African American participants with lived experiences with accessing behavioral health care services in Saginaw County for mental health or substance use disorder within the past five years. The project included engagement with other local stakeholders throughout the project. This project laid the groundwork for making data-informed recommendations for potential systems-level change driven by community-led understanding of the barriers.

METHODOLOGY

Community-based participatory research is a collaborative approach to research that focuses on equal participation between the researchers and the community being studied. It seeks to build community capacity, improve health outcomes, and, at times, enact policy or social change within the community. Qualitative, community-based participatory research is about immersing the research in communities, recognizing and engaging community stakeholders with whom we work, and bringing our creative and authentic selves into a discovery process that fosters exploration and understanding. Our project completed a stakeholder self-assessment and utilized a combination of interviews, listening sessions, and a county-wide survey as a means to gather data from a purposeful sampling of Saginaw County residents who had lived experience with our local behavioral health care system within the past five years. We also sponsored a data dive discussion so that we could explore local data that also looked at racial disparities in behavioral health care.

Our objective was to learn about the lived experiences of African American behavioral health care clients and to establish an understanding of the barriers experienced by African American behavioral health care clients that inhibit receiving follow-up care.

INTERVIEW/LISTENING SESSION RESULTS

We employed a collaborative approach to completing our coding and data analysis. We convened as a team of stakeholders and participated in coding training, inter-rater reliability exercises, and the co-construction of a priori descriptive coding legend. We divided the data from the interviews and listening sessions equitably and allowed ample time to read and code the participant transcriptions. After the data was coded, we identified emergent themes based on the strength of the thematic manifestation in the data. Our results were derived from a consensus-driven data analysis process.

Our discovery process results revealed ten prominent behavioral health care barriers exist in Saginaw County. These include but are not limited to:

- **Complexity of the behavioral health care system**
- **Poor treatment experience**
- **Cultural mismatch with providers**
- **Social stigmatization**
- **Inconsistent providers/access**
- **Challenges**
- **Mistrust issues**
- **Overuse of prescription drugs**
- **Communication challenges**
- **Religious beliefs**
- **Consumer self-accountability**

The following passages present direct quotes from the interview and listening session participants that illustrate significant findings that align with the respective theme unearthed during the discovery process.

Complexity of the Behavioral Health Care System

It is commonly acknowledged that the behavioral health care system can be complex and difficult to navigate. Our participants shared their perspectives and experience that corroborate this theme. Participants reported:

> Sometimes it took like a while to get in— you know, to get an appointment. I can remember one time—yeah—it took me forever to get an appointment, and then when I got in that appointment, I'm thinking I was gonna get some medicine cause I was really needing my medicine at that time. Then I had to wait again to go get another appointment a whole month later to get the medicine, and I had just said forget it, and substance abuse was in the way. (Interview 1)

> My psychiatrist, he decided to retire and told me at the last minute. And I, with my insurance, it's hard to find one. I went through community mental health, they put me in an outpatient thing, and I got a letter earlier this month told me, "Well, we are putting our resources to better use. Your thing ends at the end of the month, so you got to find somewhere else to go. (Interview 1)

> That's why we have high turnovers where we can't, once we get in there good with someone we trust that's servicing us, we do not like that high turnover where we got to start all over and tell our story. That's traumatizing us more. (Interview 2)

> All they pretty much did was just give me a piece of paper with contact information to all of the mental-health numbers that you can call. And then you basically just make an appointment and go through the system. (Listening Session 2)

> I believe because something happened with the insurance, something like that. So, she gave me referrals to go to somewhere else though, but I just haven't found anywhere. (Listening Session 10)

> I'm still going through the paper, the sheet, going down it, is there different facilities? And I'm like, oh boy, what? Where to go? (Listening Session 10)

Complexity of the Behavioral Health Care System, *continued*

Frustrated, overwhelmed, kind of like defeated, kind of like, what am I doing this for? Have a lot of questions, but I feel frustrated and overwhelmed and defeated because now it's like, okay, now I have to say to this person the same thing that I said to the other person, but I don't really want to tell this person. Because I don't know this person. It becomes frustrating to where it's like, okay, I'm not going to give out as much as I should because why? When I'm just going to have to talk to somebody else and then why am I doing it? And then when I say, "Well, I'm not going to do this anymore. What's the point of doing that?" And then I find myself in trouble emotionally and like, "Oh man, I need some help". And then I feel if I don't keep in contact, then I won't have my meds. And if I don't have my meds, then I'm in a world of trouble because I find other ways of trying to cope, which is self-destructive. So, I just get confused and frustrated and overwhelmed. (Interview 19)

The discouragement of it is that I was looking for the outcome help that would solve my issue and that, where I couldn't get. I couldn't get it because I didn't qualify for it because I was not going crazy, pulling my hair out my head or just doing damage to my body because I'm not getting the help. (Interview 35)

But they portraying to be the people that you can go to get the help. It's almost like it's a fraud. Unless you're going, already did some kind of physical damage to yourself. You already psychologically just… Like it's no turning back, you done. It's like they're not trying to help, unless you are… It's almost like you have to already committed a crime for them to help you. The whole thing, I thought it would help before the crime is committed. That's what I feel about it. (Interview 35)

They wanted me to just keep coming back so they can get paid, and then you go to the doctor office, "You need anything?" I want to see the doctor. Sometimes the doctors ain't even there, but y'all still getting paid. (Interview 40

I can't get in there until they get the paperwork from the other place. (Interview 40)

In spite of efforts to become consumer-friendly, there is still evidence that consumers are deterred by lack of knowledge of how to effectively engage within the behavioral health care system.

Poor Treatment Experience

A poor treatment experience can be precipitated by a number of factors that affect the consumer's treatment experience. Nonetheless this theme emerged to characterize statements from participants who indicated a generalized poor experience. In those instances when participants offer specific causes for their inadequate experiences, their comments captured under a different descriptive code. Our participants shared their perspectives and experiences that reflected this theme and reported:

Before I was court-ordered mental health, I did try to go to behavioral health at … And I ended up getting into it with one of the ladies there supposed to been a counselor or whatever. Because she was asking me questions, and I was like, "I date older people and stuff." And she was like I be looking for a father figure when I date older men I didn't like what she said. And then she didn't know how to word it more appropriate, I feel. And she got hostile with me, and that's a trigger for me. Like, "I'm trying to tell you." You know what I'm saying? Like, "I don't think that was appropriate." But I didn't say it that way. But it was a conflict, so I quit going. (Listening Session 2)

And it's like it was frustrating to sometimes when I'd talk about what's going on, and it's like, "Oh, well, we got to talk about your goal plan." It's like, "This is your plan to get me out of here as fast as I can." But sometimes I need therapy, not just to get me on out of here, so I can just… Oh, I can just learn stuff myself. I need someone to talk to. Or some things I just go through, like something just triggers my brain, and I go through some depression. I want talk to someone sometimes, but it's like the mental-health system is just bum. (Listening Session 2)

They sent me to… in my early '20s. I used to be suicidal, OD, cut my wrists, or whatever. And from the emergency room, if they talked to me I get excited. And it's not that I'm angry or whatever, it's just that I just get excited. And if you do that, get excited, they'll take you straight to…. See, I had stays in … and stuff, and I felt like I didn't need to be there. But if you go there, they make you take the medicine. And if you don't take the medicine, they keep you longer, and stuff there, too. (Listening Session 2)

I think they just want to experiment on you with the medications that they have. And I think if they get a client, they have so much of a quota to make, and then they can get this bigger pay raise, or whatever. So, I think they're just there for the money, they're not actually there in your best interest. (Listening Session 2)

My second thing was, make more services available for the lower income people. I mean, again, we come back to the point where he was talking about schooling. You got these people

Poor Treatment Experience, *continued*

over here, get the "A" student and we get the "C" student. The people who just read the book and do what they got to do to get their education. They ain't going.... No, they ain't doing no extra. They ain't on the internet trying to find out, "What can I do." And I'm going to give you an example with that. When I went to drug rehab, the last time I asked the question, I said, "What's the latest model of recovery." And the therapist didn't even know. So, you see they... Some of them stop their education right to the point when they get the job. They're not trying to get better so they can help you better. And that's the problem. (Listening Session 4)

...There's a couple places I went, they made me feel like everything was my fault...And it was like kind of downgrading in the way they talked to you. I didn't like that. (Listening Session 4)

They sent me through so many channels, and so much paperwork, that I never, ever got to get the care that I needed. They just kept spinning my wheels, and spinning my wheels, and asking, digging deeper for more information. As far as my personal things, social securities and all this stuff, they wanted all these elements of information, when they never really asked me how I was doing. So, that was a barrier. They were more concerned about their pay or how we were going to get this payment in. They never once asked me about my mental health, how I was doing with doing with all of this situation and stuff. It was a barrier. I ended up not even obtaining services... They were terrible. (Interview 7)

Well, I would say that they didn't know how to help me because they never probably been through what I've been through. So, that's how I felt. (Listening Session 10)

Yeah. It was more, some of them pushed you away but then you have some good ones that they actually sit and listen to you and make you feel comfortable. (Interview 15)

Yeah. It made me feel like I just let everything out. I'm like, "I'm here letting you out. I came here on my own and y'all just..." It was a big smack in the face. Even when I cried for outpatient. I'm like, "I will go there. If I got to sign anything." I'm like, "You guys are making me more depressed telling me that you're going to take my kids and I have not done nothing wrong to my children." I came to get help so I wouldn't do something. So that was kind of like... It made me very scared, I'm not going to lie to you. I was like... It made me so depressed as I'm eating. I just didn't want to live life no more. I'm coming to get help. Now y'all making me don't want to get to help anymore. (Interview 16)

At first, I didn't feel like I was getting treated right. (Interview 20)

Poor Treatment Experience, *continued*

I don't know. It was like prison in there to me. (Interview 20)

I went to an institution. Really, that didn't help me, because, I mean, I was just locked up for a couple days. (Interview 23)

I didn't like...They got horrible, horrible help over there. But now I sought out and went to somewhere else and it's a little better for me. But it was the way they talked to you, treat you, and tell you this and that, then some of the stuff that they would give you was false information. Just discouraging. (Interview 27)

Well, the attitudes of the professionals, the capacity, being over capacitated and the number of COVID-19 cases, and just the weight and even after the fact that I did wait all those hours, I still ended up with COVID-19. I just think a lot of room in the hospitals that they could be utilizing, they don't. It's just a waste of time, it's a waste of money. They could be using it to assist patients. (Interview 28)

The fact that it was a lot of conflict of interest. There was a lot of people that did me really bad. Even when I had lost my children years ago, they didn't hear what I had to say. There were unethical situations where they overlooked it because of their profession and I feel like my rights as a consumer was violated. (Interview 28)

I can't say I was treated... I know I couldn't go five minutes over. I know most of them be watching that clock, and I mean, it be on the dot. I kind of didn't like that. I mean, it wouldn't hurt to go five... I could be in the middle of saying something, and when them 45 minutes was up... And sometime one or two start wrapping up so to make sure I'm out in them 45 minutes. (Interview 31)

Nothing. But that wasn't just the therapist fault. That was my fault too. The reason I didn't get nothing out of it... I can't say it was my fault. I had one, all she talked about was her stuff. I thought we was here for me. We talked about how many pair of shoes she got. I knew I wasn't going... I went to her twice. (Interview 31)

Yeah, I canceled the first apartment. And she called me, and she made me another one, and she told me if I didn't make that one... And I think I canceled it because I went to the emergency room. And she said if I didn't make that one, she just going to take it I don't want help, so don't worry about trying to make another appointment. I just didn't like the way she said that. So, I

Poor Treatment Experience, *continued*

didn't go. I didn't worry about making another one. (Interview 31)

So, she's like, "Well, you can't miss another appointment or we just going to have to kick you out of behavior health." But this is only my first one. The first one was on you because you didn't show up…I just didn't like the therapist I had. I just didn't like her attitude, and I was just wasn't comfortable just being there. (Interview 34)

Well, as far as that one, I constantly was trying to seek the help. They was putting it in a nice way, "We understand your situation, but we can't help you." You would look at them as ones who have the resources and the idea where exactly I could get the help. But once it comes down to it in a nice way, they was letting me down. They didn't try to give me the help that I necessarily need. Because I'd rather prevent from something bad happen, prevent it before it happens. (Interview 35)

Me seeing different behavior health doctors or therapists… All my doctors, they always asked me if I wanted to kill myself. The thing is, is, they never asked me why. They never asked me why I wanted to kill myself, or what happened. It just seemed like they really did and care. That was the biggest issue. They just never asked why I wanted to kill myself or wanted to harm myself. (Interview 37)

Well, okay, there was another mounted on trust issue I had. I went to a community mental health place. I didn't know where to go, but I went there, and they referred me to some kind of therapist psychiatrist at that time. I was real, real young when that first occurred, and she was just as bad as the rest of them. I didn't find out quite the depths of how evil this woman was until I just got the notes last year. (Interview 38)

Yeah, he had to take time. He was getting paid for 45 minutes of service, but he acted like I wasn't even there. I don't even know if he was writing about me on the paper. And the doctor that I have, he don't really take time with this either. (Interview 41)

It should be noted that while our data highlights poor treatment experiences because we were looking for barriers, we did have participants who reported an overwhelmingly positive treatment experience.

Cultural Mismatch with Providers

Workforce shortages continue to plague the behavioral health care profession. These shortages exacerbate the inadequate supply of providers and clinicians who reflect the population served. Our participants represented a purposive sample of African American persons who received behavioral health care in Saginaw County. Our participants overwhelmingly reported that they rarely receive care from someone who shared their racial identity. Consequently, many participants experienced a cultural mismatch which they described stating:

No, I was already doing that. I had a therapist actually for the partial-hospitalization program. And I'm no longer with that therapist, because she left, so now I'm with a new therapist. But that therapist isn't really equipped for a lot of things. And I know this is probably something that for most Black people. And I don't see a lot of Black therapists. Most, if not all my therapists were white women. Two of them weren't really a problem, because they were progressive, and intersectional, and seemed to understand. But the last one just felt like just surface level. (Listening Session 2)

The white people, like he said. The white people is similar, to me, to what's been happening with you taking white, suburban kids that have had nothing to do with Blacks or African Americans. Their whole life have heard nothing but negativity about Blacks and African Americans their whole life, and then you give them police badges and guns. And put them in the Black communities and say, "Go police those people." What do you think is going to happen? (Listening Session 2)

Find more Black people who understand and increase the duration of time. (Listening Session 2)

To have them to have a better understanding of my issues, and to try to visualize exactly what we're going through, putting themselves in our shoes. (Listening Session 2)

Which one I feel like I can relate to, or that makes me feel comfortable. Instead of you telling me I got to go to her, me and her don't vibe. Me and him do. (Listening Session 2)

I don't see people that look like us in the chair listening to us. And it's like [inaudible 01:04:43] like having a Black man, or having a Black woman to talk to, that's someone that's my color.

Cultural Mismatch with Providers, *continued*

Versus a white person it's like, "Oh, well, I hope that white person isn't secretly racist." Or, "I hope that person is progressive, and intersectional, and are able to understand Black issues. And to be at bay, and just listen, and just be there." But it's like I don't see people that look like us. (Listening Session 2)

White kids can fall down the steps and need counseling and therapy. Their dad could leave their mother, and they need therapy for that. White kids get therapy for that. White kid can get caught stealing in Kmart, and, "Their dad left. He's just going through something. He just needs some love and some therapy." We don't get that. The suffering that we endure, I know now, I mean, I probably should've been dead a long time ago because of the life that I lived. (Listening Session 2)

And if you have someone of your background, they may be able to relate to you and know where you coming from compared to someone that's not… I'm not trying to be funny, I'm not trying to be racist, but someone from a white culture do not know how to relate to someone from black culture and understand what we go through. (Listening Session 4)

She was young. She wasn't experienced to me and she wasn't my color. So, she really didn't know what guys was really like more towards black women. And they just tried to fight me and she said something, "You have to fight back." I mean, things I already knew. You know, she wasn't giving me enough information what to do. (Interview 17)

I feel like she didn't understand. I feel like they need to get more educated people, knowing what they know, to deal with black people, women. Sometimes feel like you need people to experience stuff. Sometimes school is not enough. Sometimes you need to be experienced, some things. Just talk to you. I just feel like she wasn't experienced in that area. She probably went to school for it, she probably liked it and she wanted a job, but she wasn't for the job. It wasn't her. It wasn't for her. (Interview 17)

I think they need to know more about the culture of us… They don't know too much about our culture. I know the diversity, it needs more diversity, counselors for different people. To me, they didn't know more about it. You know how they say about us? (Interview 17)

Cultural Mismatch with Providers, *continued*

I wonder could I ask for a black therapist. I'm going to Google that, because I don't know why. It's just, well, the one I had, she was more caring. And you could see a person… Like they say, your eyes are the windows to your heart. You can look in a person's eyes and see they ain't even listening to you. What you're saying going right over their head. They're waiting for that 45 minutes to pass, and you can see if a person really concerned about you getting better. (Interview 31)

You kind of know on your first visit how that person is and if you're going click. Well, I knew, but a lot of times I'd still go, because I'd say, "Well, you just went one time. Give the person a chance." So, I'd go two or three more times, and it just ain't… And I wonder why all of them are different. I'm sure they all studied the same thing. (Interview 31)

Well, not being funny, but maybe if they got some Black therapists. You know how you can open up to the White therapist, but then you feel when you open up to them, okay, well I can't say too much because they might call people on me. And I get like that too. I'm not going to say too, especially like, but I feel better talking to my guy because I feel like they understand better than White folks. (Interview 34)

Okay, they got a lot of Arabs. They got all the Japanese people. Y'all can't understand half of the @%$# that we say…And then when you get a doctor in there, we only got one.., who probably is a Black guy, but you got so many people that's in there that can't understand what we talking about. You can't understand average @%$# they're saying. (Interview 40)

…When we have Black teachers and Black inspiration people, we can understand where they come from because they say it a different way than what y'all say. (Interview 40)

Participants clearly provided evidence that they were impacted by cultural incongruence between themselves and their care providers.

Social Stigmatization

Persons in need of behavioral health care services are often victimized by stereotypical thinking and outright falsehoods about mental illness and substance use disorders. Our participants elaborated on the impact of social stigmatization on their lives indicating:

They just thought I was a troubled child... They didn't talk about mental health. There was a stigma... Even when I got help, they considered that a stigma... They didn't want to discuss that. First thing coming out their mouth is black folks don't go to counselors. (Listening Session 4)

My dad's side of the family is kind of like... Well, the streets call them crazy, you know what I mean? So that's what I used to get all the time, "Oh, he crazy just like his daddy is." (Interview 23)

Well, I think now that... When I was a drug addict, it was looked on as criminal as opposed to there's an illness. So, I think when a lot of white people found themselves in this same, similar thing, then we made it an illness, and we responded better, but there's still a lot that can be done, and especially psychologically. What these people need a lot of, even people going to jail, really, is unnecessary. They have a real psychological disorder, but just treated as I was, as a drug addict. That criminal, instead of recognizing the problem. (Interview 25)

There's a lot of judgmental people, specifically Christians. So, it's good to have that type of care especially in the black community, because a lot of people think you're crazy and all types of stuff like that. They think that's an issue. I don't think that's an issue. I believe in health, mental health care for people, especially black people. (Interview 25)

I feel like... What I take into consideration before I look for mental health help or anything like that, I take into consideration other people being able to see my business or it being on my record, or it could possibly mess up any future opportunities for me, or just put a mark on me as in like people go by my time period where I wasn't myself. So, I don't want them to go by that. So that's something that scares me before I ask for help or anything like that. (Interview 30)

In the past, especially at a younger age, it was like, well, we call it crazy, mental problem, crazy.

Social Stigmatization, *continued*

And it was this stigma that they put on when you're dealing with mental health. Because honestly, I was ashamed when I was seeking therapy. It wasn't something I just would tell nobody. (Interview 31)

We already didn't feel comfortable because of how we perceived going to the therapist. (Interview 31)

People have trouble with receiving help and stuff because that label that's been on mental health. If you get the help and stuff, then that makes you weak or it makes you a certain kind of way. But I'm going all the way back to people have to feel comfortable with the right person to be able to address all the issues that they have when it comes to dealing with the mental health, and a lot of people don't have patience for people with mental health issues. (Interview 38)

You know what? It's not even the care system. It's the people of society, and how society raises them, and how society teaches them that they're better than us. (Interview 41)

Social stigmatization is often an outgrowth of entrenched misinformation. Stigma is detrimental not just to people with mental illness and/or substance use disorder, but also to the health of our society as a whole. Care needs to be taken to provide accurate information about mental health and substance use disorders so that person in need of care aren't stigmatized.

Inconsistent Providers/Access Challenges

Accessibility of quality behavioral health care can be a challenge for underserved populations who may experience constraints that others do not experience. Inconsistencies in provision of treatment can also disrupt care provision. Our participants shared their concerns with inconsistent providers and access barriers noting:

> It just became expensive and it became bouncing around from one therapist to the next therapist, because they're moving on, going somewhere else. And it's like, okay, I'm talking to this person getting very comfortable with this person and all of the sudden they're going somewhere else and I have another therapist. (Interview 19)

> Why am I telling this person the same thing when I've been talking to someone?" And now I got to start it all over three or four times with different therapists, instead of just the same one. Because I don't think that when you start over, it's like, okay, now this person has to get to know me all over again, not all over again, but I got to go through this all over again and try to get comfortable with this person or that person. And it's like that. I just feel a lot of times that I'm just telling the same stories over and over again. (Interview 19)

> A lot of places wouldn't take my insurance. And when you had to pay out of pocket so, my insurance didn't pay for it and I couldn't pay out of pocket for it at the time, so I didn't go. (Interview 14)

> ...I feel like the community needs a community center that's closer to where ... They should have a food bank and recovery coaches and all that kind of good stuff like that that's close, where a community center or something like that, that would be more helpful...Like that community center. Places where it's easy located and support and encouragement. (Interview 24)

> Well, she had told me when I went there and I think it was once or twice, she did tell me upfront, that she will not be working there. And I'm like, "Dang, I just actually opened up to you, and I really don't do that." And now I'm going to be seeing someone else, so I never went back after that. You know what I mean? (Interview 36)

Inconsistency in providers and accessibility barriers clearly need to be examined so that gaps in the behavioral health care system can be addressed with the redistribution of resources that may lessen the existence of behavioral health care disparities.

Mistrust Issues

There are those who believe that trust should be freely given while others believe that trust should be earned. Our participants indicated that mistrust affected the quality of their treatment experience. Participants stated:

> ...I've never believed in no mental-health system at all. And I've been involved with it since I was a kid. I've always rebelled against it and cannot tell you any way that I feel like any one of those mental-health counselors, therapists, and all those juvenile homes and youth homes helped me. (Listening Session 2)

> Yeah, I don't want to open up. (Listening Session 2)

> It wasn't private enough for me. (Interview 17)

> I went one time with a group session and everything they all said scared me, thinking might happen to me. So, I didn't never go back...I don't feel I should have been in a group session. Everybody knowing what's going on with them. (Interview 17)

> It took me like a couple months. I mean, it probably took me about three months after that weekend that I felt enough trust to actually talk to a therapist. (Interview 19)

> Yah. And like, sometimes I felt uncomfortable. Like they was too much. I don't know how to explain it, too close or too much. Or just, you know when something feels off or different. (Interview 20)

> I want somebody that I'm comfortable with to be able to open up to them, because if I'm not comfortable I'm not going to really open up. (Interview 34)

> I didn't trust none of them and stuff, because now I'm much wiser, much older and I comprehend and understand things a lot better. I always talk to people to see where they at before I even go too far, because this outward appearance is really deceiving in the workplace, especially when it comes to therapy, that kind of stuff. It's sad. Like I said, I wrestled with that, I couldn't trust nobody... I think mainly my main problem was I was looking for somebody that I could trust. (Interview 38)

It would be inappropriate to understate the importance of trust. to build trust can help to address the mistrust that some consumers may harbor. When all else fails the best way to build trust is to be trustworthy.

Overuse of Prescription Drugs

Use of prescription drugs can clearly be a part of a viable treatment plan. While this is true, it is important to note that consumers must feel that their voice is being heard and valued with regard to the effectiveness of prescription drugs. Many participants indicated that they felt that prescription drugs were being over prescribed:

They looked at it, they took the bottle, and they tossed it out there in the ocean. Because I was just like a zombie. And I didn't even recognize that within myself, but they could see the difference in me. And so, I got back on the other medication that I'm on now, Cymbalta. And I don't take anything else [inaudible 00:26:41] because they gave me the shot that lasts for three months, one time. And that's not good, neither. Because it puts you in a trance-like state, and I don't want to be like that. (Listening Session 2)

And for a while, I would actually be on medication, like everyone here talk about. And at one point, it was okay. But all the medications, it made me feel like a robot. It made me feel like I was a shell of my former self. And there was a time where I was on medication, and I was looking at pictures of myself, and it's like I can't even recognize myself. (Listening Session 2)

I felt like I was just blurry, like I was in a different family. I thought my mom was an adopted mom, or something, and like I was just adopted, or… I was really low. Especially if I miss a couple days to be on the medication, it will really show in my behavior and how my mood swings. And [inaudible 00:29:00] diagnosed with a form of PTSD. Being diagnosed with, I don't know which type of bipolar, because I even tried to make sure that I was… I wanted to work on myself. Like I was part of a PHP, a partial-hospitalization program for a few days, and having more medications, I just couldn't deal with. (Listening Session 2)

But when you go seek counseling, the first thing they want to do is give you a quick diagnosis and throw you on drugs. (Listening Session 4)

And then my body got back regular after I left the medicine alone, like in a month or so, it got back normal. But see, I'm back at the same services so I'm just going to tell my people, "Look, lighten up off the medicine" or whatever. (Listening Session 4)

Overuse of Prescription Drugs, *continued*

I had them one time diagnosed me schizophrenia bipolar. That was my daughter. He prescribed medication for me. Medication was so strong it had me lose dates. My kids said, "Mom get off of it. You a zombie." I had to stop taking it. (Listening Session 4)

The insurance had a lot to do with that too. I took my daughter to counseling. All she needed was someone to talk to. Within a couple days, they told me they prescribed her, they had her on some meds. It could be very quickly sometimes and then sometimes it'll be over months. They keep giving you different medications so they feel that they have you diagnosed right. (Listening Session 4)

Yeah. Yes, because that medicine that Westland had me on, that stuff made my nose bleed, took all my hair out and everything. And that was not normal for me. And when I stopped taking it, it's been about maybe a year ago, a year. (Listening Session 4)

They gave me something. And it was terrible because the medication that they gave me, it was in my system for 10 whole days where my arms were just so weak. I couldn't even raise my arms up. They overdosed me, I think. (Listening Session 10)

Yeah, this is not right. This is too much medication to be taking. (Listening Session 10)

They drug me up so much that when I was in the car with my niece, I thought we was in Las Vegas somewhere because the lights were just… flashing everywhere. (Listening Session 10)

There you go. And I'm like, it was some way where the doctors, they seem like they don't care, to be honest. It seemed like you're telling them what symptoms you have or what you're going through. They kind of nodding and write you a prescription. I'm like, "People like to talk sometimes." You can't just keep… Don't keep throwing meds at me. (Interview 16)

Yes. I went back and first they wanted to give me some medication. I tried to explain, no medication. I said, "I'm in my right mind. I need you to help me, how to deal with my problem."

Overuse of Prescription Drugs, *continued*

I didn't feel like I needed medicine for that. So, I didn't go back. (Interview 17)

Well, I found out taking the medication that they was trying me on, I took the medication, but doing a drug, I couldn't tell it was working. And so, they was just study testing me on different things, to see. And I kept telling her, "I don't know if it's working or not." Well, when I realized and it came to me that doing drugs and trying to take medication, they do not mix; it will not help me none. So that's probably why I couldn't see the difference in the change of my behavior or my train of thoughts. (Interview 22)

So, now I be skeptical of what I take. And I tell them, I be upfront with them at the therapist. Like, "Don't be trying to prescribe me this, this, this. I'm a tell you upfront I'm not going to take it." (Interview 34)

Some doctors have prescribed stimulant medications. Neither of my doctors have tried to prescribe that. And the crazy part is this, I actually used to be on Ritalin in Concerta, as a kid in as a teenager. They're not listening to me as far as that, they don't want to prescribe me steroids all the time. And here's the thing, whether they prescribe medicine or whatever they want to prescribe, it all has a side effect. You don't know if it's going to work for me or not. So, I'm already being a guinea pig because you trying stuff on me anyway. So, I don't know, but like I said, I'm tired. I just wish they'd figure it out. So, I just don't really want to go because nothing is really being done anyhow. (Interview 36)

Prescription drugs can be of great when they are part of a collaboratively devised treatment plan. Consumers are less likely to think that prescription drugs are being overprescribed when they are active contributors in determining their treatment plan.

Communication Challenges

In order for communication to be effective, it must be two-way between parties who feel heard. Our participants indicated that they either felt unheard or misunderstood. Participants stated:

So not just the time, but the time limit, the time that you're given. Like I had 45 minutes when I had my previous therapist. And within that 45 minutes there are things in my head that I just needed to say. Like, "Oh, there's something that's happened." If I go off tangent, and just discussing all the issues. And then just trying to make sense everything, or try and get deeper. My last therapist would be like, "Well, hey, Participant 4, you want to get back to the topic, please? I'm not following." And it just screws up my entire... Everything I'm trying to make sense of is just, it stops making sense. I am pulled back, and I get really aggravated and be like, "Oh, well, I know what you're saying." And it's like that's just my number-one mood killer. Like, "Just listen." (Listening Session 2)

And making their determinations based on the fact that she's the adult and he's the kid. If they would've listened to me and did some real research, meaning if you really have my interest at heart. I told you I'm being abused, and neglected, and starved, I'm hungry. I'm stealing to eat and feed my sister. "No, you're stealing because you're bad, and because you want to steal." "No, I'm stealing because me and my sister don't have food to eat." (Listening Session 2)

That's why I said we not Guinea pigs. Just sit there and talk to us, get the feel of us over time, and then you'll be able to give us the right medication. (Listening Session 4)

What stands out in this area is when you go for service and the provider tries to dumb you down or speak to you as if you have no intellectual ability to process what they're saying. It annoys me, and lots of times I will let that be known. (Interview 7)

I said, I feel like I was going to fall asleep. I was dozing off somewhere in my mind when she was talking. I wasn't really paying attention... Well, I feel like I would tell her something and then she'd be like... I forgot kind of, I really don't, honestly remember. That's how much it didn't help. (Listening Session 10)

And I keep telling them, because we did this before with that medication, "Don't give her that medicine no more." And they turn around, keep doing it, they don't listen to what I'm telling them. They ignore me. (Listening Session 10)

Communication Challenges, *continued*

So, I said, listen to patients more. Is one thing that I think should be changed. Listen to patients more. (Listening Session 10)

Yeah. They can listen better. I think they need to listen to the patient. Like if a patient knows something's not working for them, and anybody should know their body better than anybody else. So, if something's not working for you, the doctor should know, "All right. Let's try something different." (Listening Session 10)

Sometimes there was a lack of communication between the patient and the doctor...I don't think I had a chance to speak with the doctor about my health concerns enough. I didn't see him as often as I should. (Interview 11)

I want to feel comfortable and talk to somebody else and get their opinion. But instead they just like, "Nah." So now you're like, "I'm done talking to you now." Because I'm not getting the connection that I need with this person. And it's so quick. And I was like, "Can you guys hear me out? (Interview 16)

If you're having a conversation with them, you're trying to express yourself, you can see they don't want to be bothered or really want to listen to what you're saying. You know? It makes you feel very uncomfortable. So now you're sitting there like, "Who should I talk to? Am I talking to the very person? Or am I talk to the wrong... Or are they really listening to me?" It's more of a push away. So now I'm back like, "I just said all that, somebody didn't even care." That was my whole purpose to come here to get that help or to talk to somebody. When I can't talk to my mom or someone, talk to somebody else different, because I didn't want to worry my mom. So, I went there and I felt like I wasn't getting what I wanted. And sometimes people just want to talk. Yeah. And somebody to hear them out. So, I pretty much wasn't getting that. So, I would give that like a three. (Interview 16)

So that was one thing that scared me. So, I'm like, "You got to watch what you say. You actually can't just go in there and just speak your mind. You feel like you got to go like that. Ever since then, that's scared me. I'm like, "I haven't harmed my kids. I came in, I reached out to you guys for help and now you're telling me y'all can get a court order that I stay here and take my kids?" (Interview 16)

Communication Challenges, *continued*

Me on medication. I'm like, "I just say a few things and here y'all just throwing me a script." And then so when I'm reading the scripts, I'm like, "Okay, this one says..." And I'm telling them like all the stuff that I had when I went to the doctor with constipation and stuff. So, me being who I am, I always read my medication and see the side effects. So, I'm like, "They give me other medicine that I begged not to get." I asked them, "I don't need nothing to make me super sleepy. I do have three little kids." I'm trying to get myself better. They give me something for that. And I have problems with my stomach. So, they give me stuff like in order to make you get constipated. I'm like, "Are you guys hearing me out? Are you hearing me out?" (Interview 16)

Okay. So, I'm talking to her and she's moving slow. And to me, she just threw me any type of medication. So that would cause me to something like, "Hey, she didn't listen." And I said, "so that's what caused me to start reading my medication." Because you didn't tell me all this could happen. (Interview 16)

I'm kind of embarrassed to say something because, to me, they already make us feel like we're crazy. I'm going to be honest. They make you feel like something's wrong with you. So, I was kind of scared to tell them like... Or I don't want them think like, "Oh, she's a hallucinating or she's this." They give you medication to make you hallucinate, too, as well, because I had some medication that said to make you hallucinate. (Interview 16)

I was telling them I didn't want all this medicine. So, but I was trying to take it. It got to the point where my mom had to call because I had too much medication. Honestly, I went cuckoo. So, when I got in there, I pretty much slept. (Interview 16)

It's like she wasn't listening because she was too focused on trying to gather herself, which I know she's new, so I was being patient. But I'm like, "Okay, you could've had listened to me a little better. Now look at me. Now I'm up in the mental house and waking up the next day I don't know where I'm at." (Interview 16)

Only problem that I pretty much had, if I would call and I need to get through to someone, the way their phone service works and stuff, sometimes I could be left on hold for a long time before I get switched over. Or I'd get bounced around until I get right to the person. (Interview 22)

They should start listening to the mothers and believing them and stop putting people on

Communication Challenges, *continued*

medicine, they really don't need it sometimes, because that's wrong. I feel like that's wrong. (Interview 32)

That's a hard one to answer, but what would make it easier? I don't know. Probably if they would listen to my side more than me listening to theirs, because I don't think they know my life and that's all that run through my mind that they kind tell me what going to happen in my past, some of that nature. And that's what makes me just get the notion to not want to listen or not want to participate. (Interview 33)

Treatment? Well, sometimes it seems like they don't listen, you know?... Yep. They weren't listening, because if you check my record and I don't know how far you can go back, or if you can even get it like as a kid, I used to be on Ritalin and I was on Concerta. That should be on my file, so it's not like it was anything new. It was just, I'm tired all the time. I just feel like if I have a problem sleeping, they have no problem giving me a medication to help me sleep. You know what I mean? But when I'm telling you, I'm tired all the time, you don't want to give me anything then to keep me up and I'm tired all the time. And then not only that, they diagnosed me with ringworm for five years, I was taking medicine only to find out I had lupus. (Interview 36)

I would say I think, and maybe I'm wrong about this, is I try to tell them what's going on and they don't listen, or it seems like nothing happens. (Interview 36)

I knew I was going to have somebody that was going to listen to me today. It ain't about no gift certificate card. Y'all can keep that, just somebody just to listen. (Interview 40)

Yeah. I went to the counselor, right? And I was talking to him and stuff, but he wasn't listening. That's why it took me a long time to get meds. (Interview 41)

One of the best ways to address communication challenges is to acknowledge that a problem exists. Once this acknowledgement is made, it is much easier to fortify the lines of communication so that consumers feel seen, heard, and empowered to the central actors in the recovery process.

Religious Beliefs

Religion and spirituality can provide a great source of resilience for consumers who are people of faith. Ironically, our research indicated that while religious/spiritual beliefs were viewed as a strength, these beliefs became a barrier to behavioral health care when participants opted to rely exclusively on religion and spirituality. Our participants indicated:

When I really got ready to change, then I pursued avenues that I believed they could help me change. And the main avenue, again, was spirituality for me. All the way through the prison, and through everything was not just because grandmamma said, "Go to church, and Jesus this, and Jesus that." for all those years. But to really pursue an understanding for myself when I got to that point. That I want to know God, and know Jesus stuff, and know what is all of the animosity about with this. When I started pursuing that for myself, started reading the Bible and implementing that scriptures, then I really started changing. And I didn't have no counselor, no therapist, no nothing. (Listening Session 2)

I had a Bible, I had getting down on my knees. And I had recognizing that, "You are involved with some stuff that I don't want be involved with, so I'm not going to mess with you. You are involved with stuff that I'm not going to be involved with, so I'm not going to mess with you. And you're cool, you're cool. Me and you, we going to be all right, me and you." I started doing that for me. I didn't have no counselor or no therapist. (Listening Session 2)

It's a blessing that I'm here, and again, the Jesus thing. Not religion, not Christianity, pursue a relationship with God for you. That helped my life so much. (Listening Session 2)

I believe in hope and optimism and the eternal spirit of one's self and one's own strength...self-determination. (Interview 12)

I had a Bible, I had getting down on my knees. And I had recognizing that, "You are involved with some stuff that I don't want be involved with, so I'm not going to mess with you. You are involved with stuff that I'm not going to be involved with, so I'm not going to mess with you. And you're cool, you're cool. Me and you, we going to be all right, me and you." I started doing that for me. (Interview 16)

I had a miraculous experience, and I know this don't fit in with you guys' program, but God miraculously delivered. I didn't go through NA, I didn't go through AA, none of that. God miraculously delivered me... Well, like I say, I didn't go through the traditional NA, and this, that, and this type of program. Really, I'm not trying to be sarcastic, but all glory is to God. I mean, really. (Interview 25)

Religious Beliefs, *continued*

> …The main person to help you the most is God…You got to put it all on Him, give it to Him. (Interview 26)

> I feel like maybe God is… what it is God that's shaking those leaves off the tree for me to fertilize and the seeds and grow and continue to pour blessings down on me and not be a part of the norm, the misery. So, He's bringing me out of that, so I just have to accept that this is what He does and this is how He's going to operate. If I want Him to continue to keep me, I got to follow suit with Him. (Interview 28)

> I had to give it to God. (Interview 38)

We acknowledge that religion and spirituality need not compete with behavioral health care. When behavioral health care professionals acknowledge the religious/spiritual identity of consumers, it can be drawn upon as a complementary source of strength and support for consumers.

Consumer Self-Accountability

An unforeseen theme emerged when we asked participants to share the barriers they encountered that impeded their ability to follow through with completing their prescribed follow up care plan. Several participants were reluctant to assign blame outside of themselves. They took personal accountability for lapses in their treatment plans and stated:

> So, I finally got honest with myself and let myself know that my mental issues really started as a kid. I had to speak out instead of closing myself in. (Interview 27)

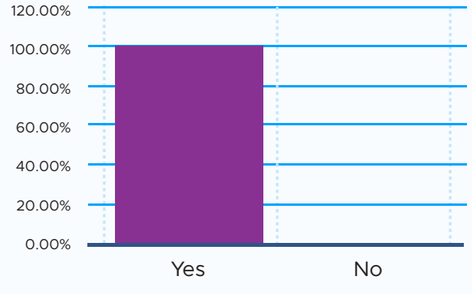
> Well, it wasn't barriers because I look way beyond that, but what stopped me probably was myself. I don't let no one else fix and pass my life. So, I blame it all on me. (Interview 33)

The unforeseen finding that consumers would identify themselves as a barrier to equitable access to behavioral health care was eye opening. While our research identified multiple barriers that can be eliminated with closer attention and scrutiny, it is equally important that we acknowledge that personal accountability should not be discounted.

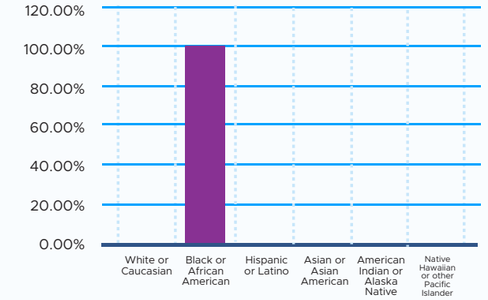
SURVEY RESULTS

We collected **122 surveys** from eligible participants. The following reflects our findings:

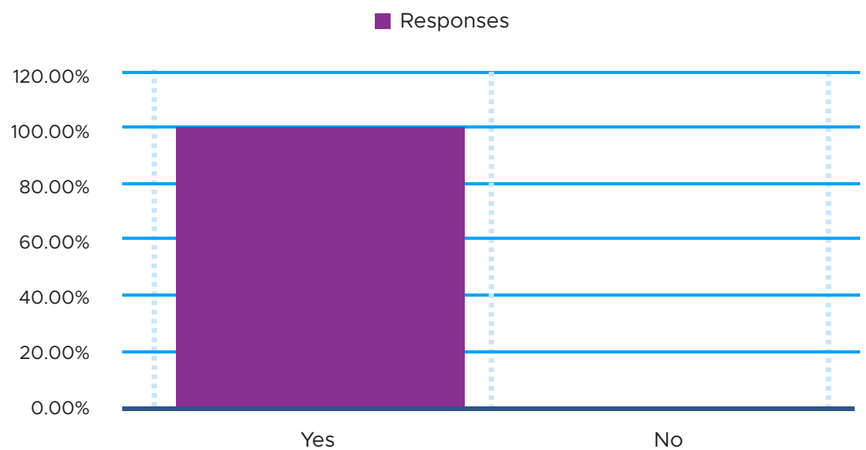
Question 1: Do you live in Saginaw County?



Question 2: What is your race?



Question 3: In the last 5 years, have you received services for behavioral health care? (substance use/abuse, mental health problems, alcohol abuse)?



Survey Results, *continued*

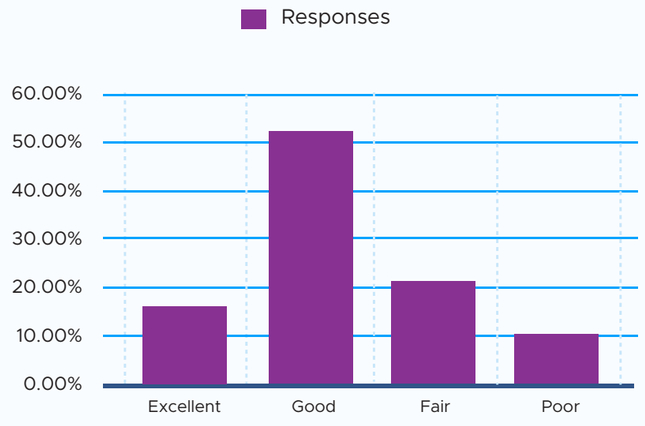
Question 4: What led you to seek behavioral health care?
Answers to this question varied. Respondents indicated a multitude of factors including but not limited to – chronic mental illness, hallucinations, hearing voices, alcohol abuse, drug use, suicidal thoughts, depression, lack of medication, insomnia, stress, family issues, and substance use.

Question 5: What did you experience when you sought behavioral health care (mental health and/or substance abuse treatment)?

- Respondents provided a mix of positive and negative experiences.
- Negative themes emerged such as – indifferent doctors, overuse of prescription drugs, communication challenges, and little to no help.
- Positive themes emerged such as – good treatment experience, great help, and someone that listened without judgement.

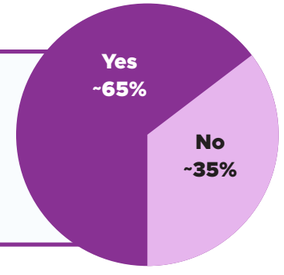
Question 6: When you received behavioral health care, do you feel that you were treated fairly? If yes, what happened? If not, what happened?
Roughly sixty percent (60%) of respondents answered "yes", thirty percent (30%) answered "no" and ten percent (10%) did not answer or were indecisive.

Question 7: How would you rate the care you received when you sought behavioral heath care? Of the survey respondents who answered this question (112 of 118), 16.24% (19) answered Excellent, 52.99% (57) answered Good, 20.51% (24) answered Fair, and 10.26% (12) answered Poor.

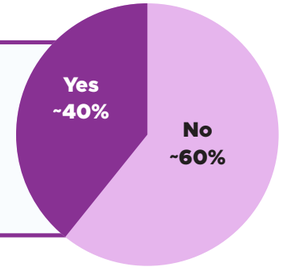


Survey Results, *continued*

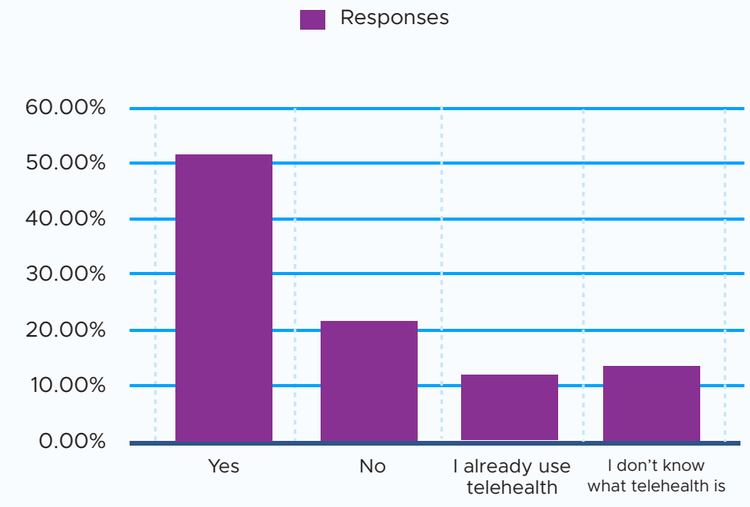
Question 8: Are you taking any medication to treat your substance use/abuse, alcohol abuse and/or mental health problems? Roughly sixty-five percent (65%) of respondents answered "yes", thirty-five percent (35%) answered "no".



Question 9: In the last 5 years, have you ever initiated behavioral health care by going to your doctor or seeking medical emergency room assistance and failed to complete the recommended follow-up care? The majority (nearly 60%) responded, "no".

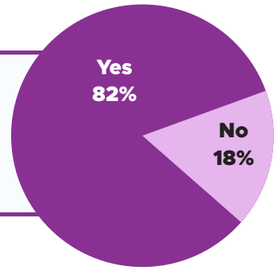


Question 10: Would you be interested in receiving behavioral health services through telehealth? Results were mixed.

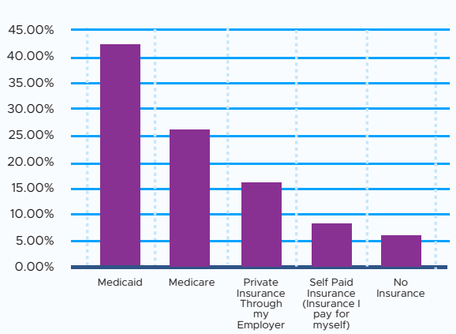


Survey Results, *continued*

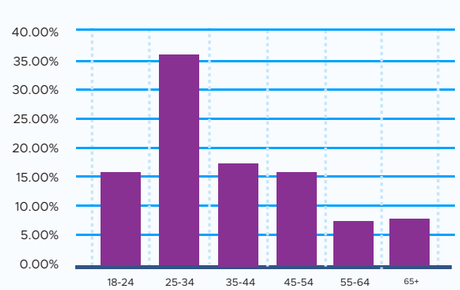
Question 11: Do you have a primary doctor?
The majority eighty-two (82%) responded, “yes” and eighteen percent (18%) responded “no”.



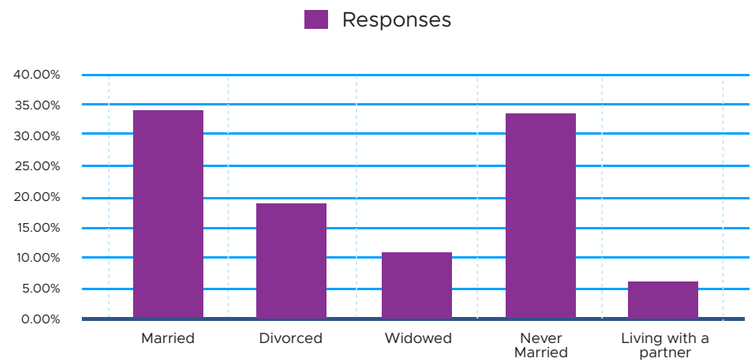
Question 12:
What type of health insurance do you have?



Question 13:
What is your age?

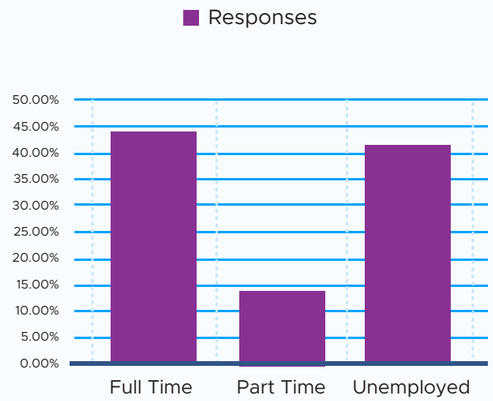


Question 14:
What is your current marital status?



Survey Results, *continued*

Question 15:
What is your current employment status?



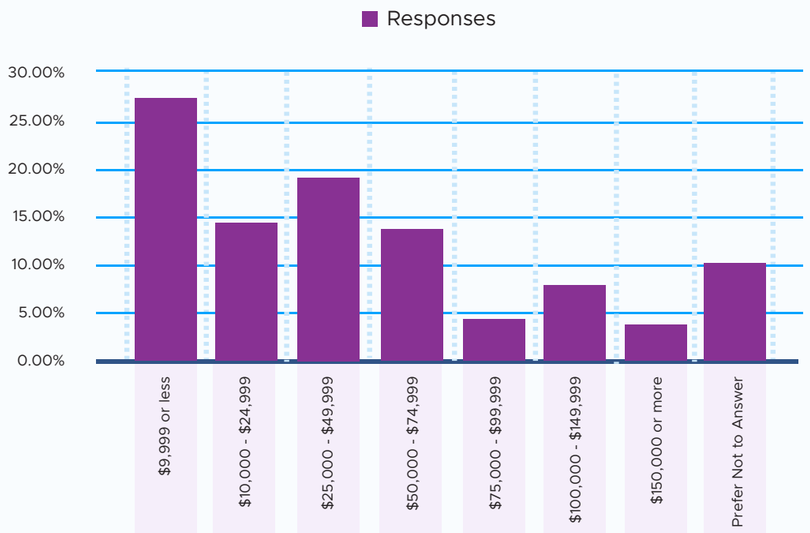
Question 17 was open-ended and asked – Please provide anything else you would like to share about your experiences with receiving behavioral health care.

The seventy-eight (78) people responded spoke about the positive benefits of behavioral health care, the need for more behavioral health care community resources, the need for more diversity amongst providers, and their firsthand experiences with racism, and bias. Forty-four (44) people did not answer this question.

Question 18 was open-ended and asked – How are you currently feeling?

Roughly eighty-eight percent (89%) of survey participants answered this question. Answers varied greatly.

Question 16:
Which best describes your income?



RECOMMENDATIONS/CONCLUSION

There is an incontestable need to abate persistent racial/ethnic disparities in access to quality behavioral health care. Saginaw County demographic trends reflect typical of national trends. It is clear that disparities will not improve without proactive measures. Working in collaboration with our stakeholders, Women of Colors has devised a list of recommendations that can lead to community-informed solutions if acted upon. We offer the following recommendations:

Community Partnerships: Providers need to sustain partnerships with community-based organizations that can support them in addressing the unique challenges in racial/ethnic minority communities. Strategic partnerships with cultural informants can support providers responding to persistent disparities in an impactful manner. The aim of the community partnerships should be to center the experiences of underserved minority populations. Partners should be trusted cultural leaders from the community who can share the language, culture, customs, traditions, and values of the people they represent and can share valuable and potentially lifesaving behavioral health care information. This CPR can evaluate existing behavioral health policies that affect practice to determine whether they are producing the intended outcome; if they are not, the group will work to change them, so they do. These partnerships can create a space to assess the behavioral health care system and its ability to interface with minority communities as well as gather cultural informant data to affect community public health policy.

Provision of Cultural Competence Training: Behavioral health providers need more training on minoritized populations specific needs and culture. Many racial/ethnic minorities have challenges accessing appropriate care because providers lack cultural competence to help engage and support them in treatment.

Education Campaign: It is important to raise awareness about substance use disorders and mental health disorders through education and advocacy and less stigmatization. The goal of such a campaign is to make people conscious of the impact of behavioral health care and to arm them with accurate information.

Policy Reform: It is beneficial to have a diverse stakeholder body involved in the review and reform of policies that can support the provision of effective behavioral health services. In developing behavioral health policy, it is important to be cognizant of stigma associated with mental health issues, mental illness, and substance use disorders. Social stigmatization of persons with behavioral health care needs results in detrimental outcomes. Social stigmatization also contributes to social exclusion of people with mental illness and/or substance use disorders. When policies are not appropriate, they can foster exclusion rather than full social inclusion.

Community-based Participatory Research: Community-based participatory research (CBPR) is a collaborative approach to research that involves collective, reflective and systematic inquiry in which traditional researchers and community stakeholders engage as equal partners in all steps of the research process with the goals of educating, informing best practices or bringing about social change. Providers need to diversify data sources that inform system-level decision-making.

Recommendations/Conclusion, *continued*

Building local capacity for collaborative research on behavioral health care with a focus on underserved communities should be prioritized.

Sponsored Community Conversations: Community conversations give people a chance to learn more about behavioral health issues. People who participate in these conversations can discuss issues related to mental health and share ideas for acting to improve mental health in our communities. By sponsoring community conversations, providers and community-based organizations can debunk myths about metal health issues, increase awareness about substance use disorders, empower others who may need help with perspectives they can relate to, and increase public awareness about the pervasiveness of mental health challenges and substance use disorder.

Consumer Advocacy: The provision of culturally responsive behavioral health advocates who are people in the community with mental health and/or substance use disorder experience is a proactive measure to support underserved populations. Advocates will provide support to those with mental illness or substance use disorder. This support can come in many forms, including providing emotional support and advice on dealing with their health challenges. Advocates will offer encouragement and hope, but they can also advise about what has worked for or is working for them. Advocates will become role models of someone who managed their illness successfully and are now using their experiences to help others going through the same things. Advocates will highlight the availability of resources in their community, which is necessary for people to seek help when they need it. Advocates health or substance use disorder feel more comfortable sharing what they are going through when in the presence of someone who has been there before. Advocates will give a voice to people who would otherwise not have one. Advocates listen, advocate for them, hold them up, and fight alongside them.

Wellness and Prevention: Proactively maintaining wellness is a means to positively manage physical and mental health. When mental health and substance use disorder are an issue, wellness cannot be taken for granted. Those in recovery need a culturally responsive prevention process for becoming aware of how to make healthy choices to achieve a healthier quality of life. Wellness activities may include sewing, knitting, mindfulness, meditation, exercise, to name a few possibilities. During these wellness classes, participants will also have an opportunity to interact with behavioral health care professionals who will provide wellness check-ups. The aim of prevention and wellness is to allow participants to experience the benefits of integrating wellness promotion into a full recovery plan.

Workforce Development: Workforce shortages make is essential that attention is given to recruiting and retaining highly qualified and competent workers. One way to retain workers is to create opportunities for professional growth and development. Job-imbedded professional learning can also support providers in assuring that their desired reformed initiatives are well supported throughout their organizational culture.

Provider Diversification: Saginaw County needs more diverse behavioral health providers and providers who represent racial/ethnic minority communities. Ideally providers should mirror the population backgrounds or reflect the community within the geography being served.

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APPENDIX A: WOC STAKEHOLDERS' SELF-ASSESSMENT SURVEY RESULTS

Racial Disparities in Behavioral Health Follow-Up Care Project // 23 Participants

Q2 – Age
- 60-74 (47.83%)
- 45-59 (39.13%)
- 31-44 (13.04%)

Q3 – What is your race or ethnicity?
- African American (81.82%)
- White (13.64%)
- Bi-racial (4.54%)

Q4 – Describe how you see the need for this community-based participatory discovery project? (Please offer a detailed answer)
- We need to identify the barriers African Americans experience and understand why the disparities exist, how our institutions contribute to the problem, and fix the system
- To ensure equitable health to all populations

Q5 – What areas would you like to see addressed as part of our stakeholder discovery and planning process? (Please select top three answers)
- Stigma of behavioral health and substance abuse disorder in the African American Community (27.87%)
- Systemic and structural barriers (21.31%)
- Lack of communication and awareness of accessible programs (19.67%)

Q6 – What resources are the most vital for understanding the disparities? (Select top two answers)
- Focus groups with citizens who have behavioral health care lived experiences (41.86%)
- Mapping resources in the community [treatment programs, providers, financial resources, community health workers/nurse navigators, etc.] (34.88%)
- Other: One-on-one interviews and deep dive into processes and procedures between agencies & systems

Q7 – What Saginaw County data is needed to understand the problem? (Select top three answers)
- Behavioral health follow-up rates (27.78%)
- Treatment services and programs offered [e.g., inpatient, outpatient, medication assisted treatment] (23.61%)
- Who is served (16.67%)

Q8 – Based on your role in the community, where do you see the most need in behavioral health care services? (Please give a detailed answer)
- Education (cultural awareness training; educating service providers on behavioral health)
- Access (cost & location of services; easier access to psychiatry; more providers needed; insurance acceptance)
- Intake & treatment (competent staff; environment culturally inviting; need a one-stop shop program)

Q9 – How do you think we can work best together to meet the goal of recommending potential systems-level change? (Select one)
- Facilitating listening session (33.33 %)
- Other (33.33%)

Appendix A: WOC Stakeholders' Self-Assessment Survey Results, *continued*

Other Responses: one-on-one sessions; collaborate discovery plan and execute it; analysis of the systems and their processes of who carries them out and how they are carried out; choosing individuals/leaders with a genuine passion for decreasing health disparities and not just someone who qualifies because of their educational background because education doesn't guarantee that someone will be persuaded to care

Q10 – What are the biggest barriers to our team working together successfully? (Please share)
- Communication (lack of listening & understanding each other; not allowing everyone to have a voice and participate; being respectful of other's suggestions and recommendations when they are different)
- Leadership (lack of clear direction and defined roles and responsibilities; meetings that readily get to the issues; a clear process for accomplishing our mission)
- Trusting (lack of trusting each other)
- Focus (losing focus of the clients' need; losing sight of the intentions that caused us to gather; wanting to use individual models rather than coming together as a group; lack of empathy and people who don't care at all)
- Time (finding the time to meet; workday meetings; offering zoom meetings)

Q11 – What ideas do you have about building collaborations in the community? (Please share)
- Communication (listening sessions; dissemination of this project information to health providers)
- Outreach (working with the Sheriff & Warden; churches; inviting new stakeholders to the meetings)
- Using the collection impact model

Q12 – Does the organization you work for/with have administrators, service providers or clientele that you feel we should gather information from for the project?
- Yes (66.67%) No (33.33%)

Q13 – Are you willing to enlist their participation in the project?
- Yes (100 %)

Q14 – Can you provide information on how your organization works with your client population we are looking to gather information from for this project? (Please give detailed answer)
- Advocacy support for unfair/unequal treatment; workshops, forums; counseling; psychiatric care; recovery coaches; MAT; WIC; direct patient care; therapy; education in project & program coordination; teach life skills to the public, juvenile center, & jail; case management

Q15 – Are you or members of your organization willing to share knowledge by being an informant in this community-based participatory discovery project?
- Yes (87.50%)
- No (12.50%)

Q16 – What is your preferred means of participating?
- Focus Group (60%)
- One-on-one Interview (30%)
- Open-ended Survey (10%)

Q17 – Does your organization have data that is relevant to racial disparities in behavioral health follow-up care that you are willing to share? If so, please describe the data.
- No (76.19%)
- Yes (14.29%)
- Possibly (9.52%)

APPENDIX B: INTERVIEW PROTOCOL

Racial Disparities in Behavioral Health Follow-up Care Grant One-on-One Interview Script

Introduction:
Good morning/afternoon/evening

My name is _____. Thank you for agreeing to participate in this interview.

The aim of this interview is to learn about your experiences with behavioral health care treatment in Saginaw County to help us understand any barriers to care that you may have encountered. Our ultimate goal is to gather information to help improve care so that the system works better for everyone. The interview will last about forty-five minutes. I will be asking you to recall the most recent and any relevant experiences you've had within the past five years with behavioral health care in Saginaw County.
I want you to feel comfortable sharing your perceptions. There are no right or wrong answers.

SKIP CONSENT OF NARRATIVE IF IT IS DONE IN ADVANCE
CONSENT FORM INSTRUCTIONS:
Before we get started, please take a few minutes to fill out the consent form and sign it.
(Hand interviewee the consent form. After the form is returned and you have verbal consent to record, turn tape recorder on and begin the interview.)
Thank you for filling out the consent form.

[Consent to Record]
Do I have your permission to record this interview? The recording will allow me to capture the interview while paying attention to our conversation. I assure you that your identity will remain confidential when we share the interview results.

If Yes, proceed with recording If No, don't proceed with recording and end the meeting

With your permission, I will start the recording. Please let me know if at any point you want me to turn off the recorder or keep something you said off the record.
Before we begin the interview, do you have any questions? *[Discuss any questions]*

One-on-One Interview Questions:
For clarification purposes, this interview will be focusing on behavioral health care as it relates specifically to mental health issues or substance use disorders.

Q 1. What led you to seek behavioral health care for mental health or substance use disorder?

Q 2. Have you experienced an alcohol problem? If so, please describe the care you received.

Q 3. Have you been diagnosed with mental health illness? If so, please describe the care you received.

Appendix B: Interview Protocol, *continued*

Q 4. Do the people in your life support you in receiving behavioral health care?

Q 5. What stands out in your mind about your experience when you sought behavioral health care (mental health and/or substance use treatment)?

Q 6. When you received behavioral health care, do you feel that you were treated appropriately? Explain what happened?

Q 7. Have you ever initiated behavioral health care by going to your doctor or seeking medical emergency room assistance and failed to complete the recommended follow-up care? If so, why didn't you complete your follow-up after your initial visit?

Q 8. Reflecting back over the past five years, have you experienced barriers that prohibited you from receiving adequate behavioral health care in Saginaw County?

[Q9 is optional if the interviewee expresses a response to Q8 that indicates a barrier he/she experienced.]
Q 9. What do you think can be done to remove the barrier(s) that you experienced?

Q 10. Is there anything else that you would like to share about your experiences with receiving behavioral health care in Saginaw County?

Interview Closing:
Thank you for participating in this interview and for sharing your experiences with me. Is there anything else you would like to share?

Over the next few weeks, we will be transcribing the recording of our interview and reviewing it. If I have additional questions or need clarifications, may I call or email you?

Yes _____ No _____

Interviewee Name:_____

Contact Phone: _____

Contact E-mail: _____

Again, I want to express my appreciation for your participation in this interview and for sharing your experiences. You have my contact information, so please feel free to let me know if you have any questions or concerns.

Give the gift card to the interviewee.

Appendix B: Interview Protocol, *continued*

INTERVIEWER NOTE TAKING/REFLECTION INSTRUCTIONS:

General Probing Questions

- Anything else?
- How do you mean?
- Could you tell me more about your thinking on that?
- Would you tell me what you have in mind?
- What do you mean?
- Why do you feel that way?

Research Supported Interview Probing Areas:

- Stigma of needing behavioral health care
- Financial constraints
- Lack of trust of behavioral health care providers
- Mental health services/practitioners (how have helped/hindered)
- Reliance on Religion/Spirituality
- Accessibility of care
- Cultural responsiveness of care

Interviewer Reflection Notes

After the respondent leaves the room, please take a couple of minutes (in a few words) to indicate your reactions and observations about the interview. Please submit your interview notes and reflection notes with the recorded interview.

Interviewer Name:_____

Interviewee Name:_____

Date of Interview:_____

Please describe the interviewee's attitude toward you and the interview:

Please describe any unusual circumstances and/ or events that had any bearing on the

interview such as interruptions, communication difficulty, etc.:

Please describe anything else that happened during the interview that has any bearings on the interview process:

Additional comments:

APPENDIX C: LISTENING SESSION PROTOCOL

The Women of Colors (WOC) organization in collaboration with various Saginaw area community stakeholders will be conducting a series of listening sessions (group interviews) as part of multi-faceted information gathering process. The overall **discovery** effort is aimed at learning about the lived experiences of African-American behavioral health care clients. Further, the intent of the effort is to understand the barriers experienced by African-American behavioral health care clients that restrict or inhibit receiving follow-up care/services.

Simply stated a listening session is a group interview technique consisting of a small number (8-12) of participants who have lived experiences with the phenomena being investigated. Their reactions to questions are recorded and analyzed. Listening session are used as a tool to understand better people's reactions to concepts, products, services, or participants' perceptions of shared experiences. The discussions are typically guided utilizing a series of structured questions but can be totally open. Listening session by design involve a process or method to collect qualitative data through interactive and directed discussions. Listening session can be a very useful tool for gaining understanding regarding opinions and ideas about behavioral care follow-up client services. It is a way for those leading the discovery process to listen to targeted participants share their experiences and ideas.

Outlined below is the basic structure and context for conducting the proposed listening sessions.

Mission/Objectives

Information shared with WOC indicates that disparities exist in the level of follow-up care for African-American clients encountering the behavioral health care system throughout Saginaw County.

Thus, the central mission of the proposed listening session is to collect community input identifying issues that impact the community's ability to more effectively deliver consistent and equitable behavioral care services to African-Americans.

More specifically, the principal objectives of listening session sessions are:

- To learn about the lived experiences of African-American behavioral health care clients
- To establish an understanding the barriers experienced by African-American behavioral health care clients that restrict or hamper their ability to receive follow-up care

Methodology/Structure

Overall, the methodology deployed to collected client input will be guided by a structured interview guide (See Appendix A). The project has targeted up to 10 in-person listening session to capture information to meet the stated objectives. Each discussion session will be managed/facilitated by co-moderators and recorded. Other aspect of the public forums will include the following:

- *Listening session interview participants* - Will consist of African-American adult clients who reside in Saginaw County and have had lived experiences with behavioral health care within the past five years. Participants should be comfortable with talking about their personal experiences with others.

Appendix C: Listening Session Protocol, *continued*

- *Utilization of a Moderator/Facilitator* - The person who runs a group listening session. She or he is responsible for ensuring the smooth running of the discussion, managing the group process and dynamics, introducing relevant issues and ideas for response by the group participants. Having a skilled moderator will contribute significantly to the effectiveness of the listening session. Key characteristics of a successful moderator include the ability to easily interact with people, the ability to remain impartial, open and unbiased, flexible, effective listener, and possess good verbal skills. All moderators for this project will be required to participate in training. Co-moderators will be utilized to the extent possible to facilitate each of the sessions. The assigned tasks/activities of each of the moderators will be pre-defined prior to the start of a session(s).

- *Location and Timing* -- Determining appropriate locations to host the listening sessions represents an important part of the planning process especially in light of ongoing COVID-19 concerns. The right locations can serve as a draw for prospective attendees and can aid to setting the tone or comfort level of participants. Among the locations to be considered are area schools, conference facilities, libraries, etc. These represent large enough venues to accommodate spacing and other COVID-19 requirements. All participants will be required to adhere to masking and other requirements. Light refreshments will be made available for participants, and each will be presented with a $50.00 gift card at the conclusion of each session. Training sessions for listening session moderators will take place the 2/3 week of January 2022. Group sessions will be conducted in February/March of 2022 with a maximum of 2 sessions per week. The time-frame for each session will be targeted for 90 minutes but not exceed two hours.

- *Participant Invitation Strategy* - Attendance at the listening session sessions is critically important to achieve our stated objectives. Thus, it is necessary to coordinate with other project implementation teams including marketing and the coordinating leadership team to devise a strong plan for recruiting participants. Area behavioral service providers will also be important contributors to the client recruitment process.

- *Informed Consent Form (Appendix A)* - Informed consent is a major ethical consideration in implementing this discovery process. Participants will voluntarily take part without being deceived or coerced. Participants in this community-based participatory discovery process will clearly understand that they are voluntarily a part of a discovery process, and they will be informed at the initial invitation to participate about what is expected of them. This information will include the purpose of the project, and group discussion process, which might influence their decision to participate in the project. Listening session participants will receive $50.00 as an incentive for their participation in the project. In this project, participant anonymity will be protected, and confidentiality will be exercised at all times throughout the discovery process. Identifiers such as names and specific facility locations will be removed in the final report. The integrity of the participant data will be safeguarded at all stages of the discovery process.

  This discovery process will not physically, psychologically, or financially harm participants in any way.

  Participants will be made aware from the start of each focus group session that they have the right to withdraw at any time. If a participant chooses to withdraw, they will not be pressured in any way to continue and will not be guaranteed the provision of the agreed upon incentive.

Appendix C: Listening Session Protocol, *continued*

All parties involved in collecting data for this project will exemplify the highest levels of confidentiality, integrity, honesty, and respect toward each interview participant.

- *Reporting Requirements* - Listening session written notes must be prepared by the individuals moderating each of the sessions. A general rule is that these notes should be completed as soon as possible after each session and copies of the notes should be forwarded to the team leader and the project coordinator.

Summary Overview of Listening Session Procedure

I. Welcome & Introduction of Moderator(s) *Personal background statement and explanation of the role of Moderator(s).*

II. Overview of Focus Group Objectives & Ground Rules *(Explanation to participants of purpose of session, key objectives, topics to be covered, provide definition of behavioral health care, recognition of personal nature of conversation, how input will be collected (secure consent to record), key ground rules and procedures, confidentiality, and how input will be used).*

III. Secure Participant Signatures on Consent Form.

IV. Participant Self-Introductions *(Each person requested to provide first name only, employment status, marital status, overall health status, health insurance coverages, prescribed medication regime, and frequency of emergency room visits in past 5 years and association to mental health or substance use).*

V. Input /Discussion Topic Area #1: Explore cause, frequency, and reasons for seeking behavioral health care services/support. *(Collect participants responses to structured questions targeting their respective individual circumstance that led to need to seek behavioral healthcare particularly substance and/or alcohol use).*

VI. Input & Discussion Topic Area #2 Explore participants experiences with behavioral healthcare service providers. *(Collect participants responses to determine the extent, character, reactions when seeking and/or securing behavioral health care service. Collect and examine reasons for not participating in follow-up care/services).*

VII. Break – 5-10 Minutes

VIII. Input & Discussion Topic #3: Explore what participants feel can be done to strengthen the provision of behavioral health care service. *(Collect participants responses to a series of formal questions aimed at what needs to be done to improve the quality of service surrounding the delivery of behavioral health care services in the region).*

IX. Closing *(Offer opportunity for participants to add additional input/thoughts on the issue of behavioral health care. Thank participants, indicate how/who they can follow-up with any questions they may have, and distribute gift cards).*

Appendix C: Listening Session Protocol, *continued*

Attachment A
Preliminary Behavioral Health Care Listening Session Discussion Guide

(Invite participants to partake of refreshments if available as they assemble)

i. Welcome & Introduction of Moderators (2 Minutes)

Thanks for accepting our invitation to participate in this discussion today. My name is _____, I will be one of the persons facilitating our discussion today. Joining me today is _____, who will serve as a co-facilitator of the session. Essentially, we will be putting some questions and topics before you to respond to. Our job is to make sure that everyone has an opportunity to offer their input to the topics being discussed. There are several different techniques and tools we will be using to make sure we capture your thoughts. Just a reminder that the session is scheduled to go between an hour and a half and two hours. We will take a short break around the 1-hour mark.

ii. Overview of Listening Session Objectives & Ground Rules (5 Minutes)

So, let's be more specific about what we will be talking about today. A number of sources have observed that there might be some differences in behavioral health care services for certain groups of citizens in our community. You are here because you've indicated you have had direct personal experience with behavioral health care services as a client. For the purposes of this discussion let me explain the phrase "Behavioral Health Care". It refers to:

Client health care treatment/services in response to mental health disorders and/or substance abuse issues.

We want to understand your experience and what you feel needs to be done to improve behavioral health care services in the region. We totally recognize that some of what we will be discussing today will be sensitive and personal for some of you. Thus, you may decline to address certain subjects.

There are a few basic rules to keep in mind while participating today:

- We need everyone to be an active participant. Talk to us, give us your thoughts.
- I'm requesting that you please raise your hand when you wish to comment.
- There are no "right" or "wrong" answers. Please respect everyone's right to have an opinion. You may disagree with position of others.
- Speak freely but remember not to interrupt others while they are talking.
- Our note taking is for reporting purposes only and will be used for analysis. Names are not attached to the notes.
- We are conducting several of these sessions over the next few weeks all information gathered will be analyzed to determine common themes and prepare recommendations to improve the quality of behavioral health care services.
- All feedback today will remain anonymous and confidential. In order to protect confidentiality, I ask that anything that is said during our session is not repeated outside of our session.

iii. Secure Participant Signatures on Consent Form

In the interest of transparency and accountability we believe that informed consent is an important part of completing this work. We are not here with any intent to deceive or coerce anyone into

Appendix C: Listening Session Protocol, *continued*

participating in the discussion. You are doing so voluntarily. We firmly commit to protect your anonymity and protect the integrity of the information being collected. Thus, we are respectfully requesting that you sign the consent form we've made available so we can collect them at this time. Are there any questions regarding this step?

IV. Participant Self-Introductions

Let's get started, we want to go around the room and have everyone introduce themselves and tell us your first name only, employment status, marital status, overall health status, health insurance coverages, and how many emergency room visits you've made in the past 5 years that were directly associated with to mental health and/or substance related problems.

V. Input /Discussion Topic Area #1: Explore Cause, Frequency, and Reasons for Seeking Behavioral Health Care Services/Support.

1. By show of hands how many of you have sought behavioral health care services specific to mental health related issues? (Note: record count)
2. Once again, by show of hands how many of you have sought behavioral health care services specific to substance disorder issues? (Note: record count)
3. Were the substance disorder issues associated with alcohol use or other substances? (Ask for show of hands – alcohol use, then other substances)
4. Finally, by show of hands how many of you have sought behavioral health care services for both mental health and substance use issues? (Note: record count)
5. On the paper in front of you write down who or what led you to seek behavioral health care services. (Ask each respondent to reveal what they wrote down).
6. If you sought behavioral health care services more than once was the who or what the same for each occasion or was it something different. If so, what prompted you seek services for subsequent visits for behavioral health care services?
7. What experiences in any aspect of your life such as associations with other family members or people, work, special or unique events helped to shape your attitudes about behavioral health care? Is there anything else that has influenced your thinking about behavioral health care?

VI. Input & Discussion Topic Area #2 Explore participants experiences with behavioral healthcare service providers.

1. Write down three words or phrases that best describe your experience when you went for behavioral health care pertaining to mental health support or substance abuse treatment. Then we will have some discussion about your experiences.
2. How many of you feel you received the assistance or services you were seeking? Yes or No. Tell us why?
3. Do you feel you were treated fairly? If Yes/No, explain what happened?
4. On a 10 scale where 1 is very poor and 10 is excellent, how would you rate the quality of behavioral health care services you received. Ok, by show of hands how many rated the quality of service 1-3, how many gave a rating of 4-6, how many are at 7-10? Please explain your ratings.
5. How many of you have sought behavioral health care assistance from your doctor or by going to the emergency room and then didn't complete the recommended follow-up care? Raise your hand if this scenario fits your situation. Help us to understand the reason or reasons why you didn't complete the recommended follow-up after your initial visit.

Appendix C: Listening Session Protocol, *continued*

6. Those of you who have actually sought behavioral health care at a local emergency room, please explain how you were treated. What barriers did you encounter? What were your expectations from the visit to the emergency room for behavioral health care?
7. What specific information were you given for follow-up behavioral care, a referral requiring you to contact someone else or another entity, a confirmed appointment referral, only general information about other community services?

VII. Break: You've been great so far. Let's take a 5-minute break. We have a few more things to cover before we are done and present you with your gift card.

VIII. Input & Discussion Topic #3: Explore what participants feel can be done to strengthen the provision of behavioral health care service.

Hi, I'm _____, and I will be facilitating the rest of the session. Thank you for your input and patience so far.

Now that you've helped us to paint a picture of your experiences with behavioral health care, we now want you to share your thoughts on what can be done to improve these services in the region.

1. On your piece of paper please write down the number one on a line. Then write down the number two on the line just below. Now, I need you write down your two responses to complete this sentence. To improve the quality of behavioral health care in the Saginaw area we need to number one: _____ and number two we need to: _____. I'm looking for two recommendations for each of you. Go ahead take a moment to write something down. Ok, now let's go around the group and tell us what you wrote down.

   Now let's talk about what you think needs to be done. Of the things we've listed what do feel are highest priorities (what will make the greatest amount of difference toward improving behavioral healthcare?

IX. Closing/Wrap-Up

- Let me offer one last opportunity for you to offer any additional comments you feel are important for us to consider on the subject of behavioral health care in general or the follow-up process.
- Thank you for taking the time to participate today. The sharing of your experiences will greatly assist our overall goal to improve behavioral health care services to African-American clients in the region. Over the next few weeks, we will be reviewing and analyzing the information we've captured from our discussion today. Ultimately it will be included in a report (all input is reported anonymously) that will be shared with a number of stakeholders responsible for the delivery of behavioral health care.
- Please remain with us so that we can distribute the gift cards mentioned earlier. Again, thanks for your time.

Qualitative Data Analysis Plan

See process detailed in the one-on-one interview procedural plan that references the role of the Discovery Interview Team. It is expected that this part of the project will follow the same series of steps.

WOMEN OF COLORS | 1000 TUSCOLA STREET, SAGINAW MI 48607 | (989) 737-9286 | WWW.WOMENOFCOLORS.ORG

APPENDIX D: SURVEY

Thank you for taking the time to complete this confidential survey. The information gathered in this survey will be used to help determine what the barriers are for people in obtaining follow up care for behavioral health problems. By answering the questions below, you are agreeing to participate in the research process. No names or other identifying information will be used in reports.

1. Do you live in Saginaw County?
   ☐ Yes ☐ No

2. What is your race?
   ☐ White or Caucasian
   ☐ Black or African American
   ☐ Hispanic or Latino
   ☐ Asian or Asian American
   ☐ American Indian or Alaska Native
   ☐ Native Hawaiian or other Pacific Islander
   ☐ Other: _____

3. In the last 5 years, have you received services for behavioral health care? (substance use/abuse, mental health problems, alcohol abuse)
   ☐ Yes ☐ No

4. What led you to seek behavioral health care? _____
   _____

5. What did you experience when you sought behavioral health care (mental health and/or substance abuse treatment)? _____
   _____

6. When you received behavioral health care, do you feel that you were treated fairly? If yes, what happened? If not, what happened? _____
   _____

7. How would you rate the care you received when you sought behavioral health care (excellent, good, fair, poor)?
   ☐ Excellent ☐ Fair
   ☐ Good ☐ Poor

   Explain your rating? _____
   _____

8. Are you taking any medications to treat substance use/abuse, alcohol abuse or mental health problems?
   ☐ Yes ☐ No

9. In the last 5 years, have you ever initiated behavioral health care by going to your doctor or seeking medical emergency room assistance and **failed** to complete the recommended follow-up care?
   ☐ Yes* ☐ No

   ***If yes,** why didn't you complete your follow-up after your initial visit? _____
   _____

Appendix D: Survey, *continued*

10. Would you be interested in receiving behavioral health services through telehealth?
    ☐ Yes ☐ I already use telehealth
    ☐ No ☐ I don't know what telehealth is

    If you already use telehealth, how has it been helpful for you in receiving your care? _____
    _____
    _____

    If no, would it be helpful for you in receiving your care?
    ☐ Yes ☐ No

11. Do you have a primary care doctor? ☐ Yes ☐ No

    If no, what is the reason you do not have a primary care doctor? _____
    _____
    _____

12. What type of Insurance do you have?
    ☐ Medicaid
    ☐ Medicare
    ☐ Private Insurance
    ☐ Self Paid (Insurance I pay for myself)
    ☐ No Insurance

Demographic Information

13. What is your age?
    ☐ 18-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55-64 ☐ 65+

14. What is your current marital status?
    ☐ Married ☐ Divorced ☐ Living with a Partner
    ☐ Widowed ☐ Never Married

15. What is your employment status?
    ☐ Full Time ☐ Part Time ☐ Unemployed

16. Which best describes your income?
    ☐ $9,999 or less ☐ $10,000 - $24,999 ☐ $25,000 - $49,999
    ☐ $50,000 - $74,999 ☐ $75,000 - $99,999 ☐ $100,000 - $149,999
    ☐ $150,000 or more ☐ Prefer Not to Answer

17. Please provide anything else you would like to share about your experiences with receiving behavioral health care. _____
    _____

18. How are you currently feeling? _____
    _____
    _____
    _____

APPENDIX E: PARTICIPANT RECRUITMENT

APPENDIX F: INFORMED CONSENT PROCEDURES

Racial Disparities in Behavioral Health Care Follow-up Grant

Principal Discovery Leader: Women of Colors

You are invited to participate in this community-engaged discovery process for the purpose of:

- learning about the lived experiences of African American behavioral health care clients, and
- establishing an understanding of the barriers experienced by African American behavioral health care clients that inhibit receiving follow-up care.

By signing this informed consent form you are agreeing to participate in an interview that is part of our community engaged discovery process. Your 45-minute one-on-one interview will be recorded. You will be asked a series of questions about your behavioral health care experiences. The interview will conclude after you have had the opportunity to offer your insights.

Benefits of the Interview: This interview will provide a deeper understanding lived experiences of African American behavioral health care clients and reveal any barriers that may inhibit receiving follow-up care. The knowledge will contribute to future behavioral health policy adoptions and funding priorities.

Confidentiality: Your participation in this discovery process is confidential. Your name will not be associated with direct quotes from your interview. Records will be kept secure and confidential. In the event of a publication or presentation resulting from the discovery process, no personally identifiable information will be shared. Only your interviewer and trained WOC personnel will have access to any identifying information provided by you.

Compensation: You will receive a $50 Gift Card for completing the interview.

Participating in this interview is voluntary. You may change your mind at any time. You may choose not to respond to any interview question or stop the interview for any reason.

If you have questions about this research study, please contact:

Kristi Phillips, Manager/Program Coordinator
Email: kris4woc@gmail.com
1000 Tuscola Street
Saginaw, Michigan 48607
Phone: (989) 737-9286
(989) 399-8775 EXT. 5

Please print your name and sign and date below to indicate your consent for participation in the interview for our discovery purposes:

Appendix F: Informed Consent procedures, *continued*

Interviewee: _____ _____
(Print name) (date)

Interviewee Contact: _____ _____
(Phone) (e-mail)

_____
(Address, City, State, Zip)

I _____ consent to participate in a recorded interview and to have my contributions included in the Racial Disparities in Behavioral Health care Follow-up Grant results.

Interviewee: _____ _____
(Signature) (date)

Demographic Information (This section is OPTIONAL)

1. What is your gender
☐ Male ☐ Female ☐ Other: _____ ☐ Prefer Not to Answer

2. What is your age?
☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65+
☐ Prefer Not to Answer

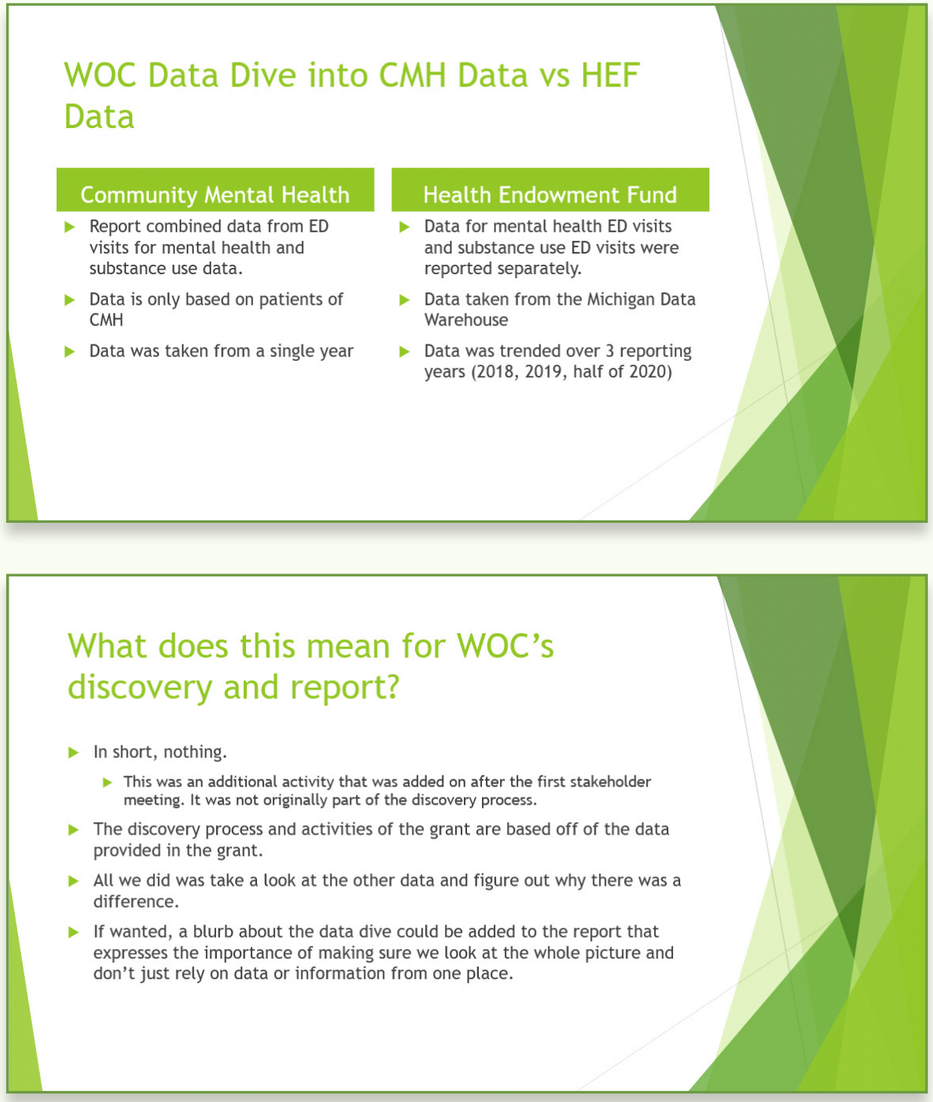
3. What is your current marital status?
☐ Married
☐ Widowed
☐ Living with a Partner
☐ Divorced
☐ Never Married
☐ Prefer Not to Answer

4. What is your employment status?
☐ Full Time
☐ Part Time
☐ Unemployed
☐ Prefer Not to Answer

5. Which best describes your income?
☐ $9,999 or less
☐ $10,000 - $24,999
☐ $25,000 - $49,999
☐ $50,000 - $74,999
☐ $75,000 - $99,999
☐ $100,000 - $149,999
☐ $150,000 or more
☐ Prefer Not to Answer

APPENDIX G: DATA DIVE DISCUSSION POWERPOINT

Appendix G: Data Dive Discussion Powerpoint, *continued*



APPENDIX H: KEY ROLES AND RESPONSIBILITIES

Racial Disparities in Behavioral Health Follow-up Care Women of Colors – Key Roles

Project Manager

- Evaluate potential problems and technical hitches and develop solutions.
- Plan and manage team goals, project schedules and new information.
- Supervise current projects and coordinate all team members to keep workflow on track.
- Manage project-related paperwork by ensuring all necessary materials are current, properly filed and stored.
- Direct project correspondences by preparing and reviewing project proposals, memos, meeting minutes and emails.
- Communicate with clients to identify and define project requirements, scope and objectives.
- Adhere to budget by monitoring expenses and implementing cost-saving measures.

Project Coordinator

- Maintaining and monitoring project plans, project schedules, workhours, budgets, and expenditures.
- Organizing, attending, and participating in stakeholder meetings.
- Documenting and following up on important actions and decisions from meetings.
- Preparing necessary presentation materials for meetings.
- Ensuring project deadlines are met.
- Determining project changes.
- Providing administrative support as needed.
- Undertaking project tasks as required.
- Developing project strategies.
- Ensuring projects adhere to frameworks and all documentation is maintained appropriately for each project.
- Assess project risks and issues and provide solutions where applicable.
- Ensure stakeholder views are managed towards the best solutions.
- Chair and facilitate meetings where appropriate and distribute minutes to all project team members.
- Create a project management calendar for fulfilling each goal and objective.

Appendix H: Key Roles and Responsibilities, *continued*

Principal Discovery Facilitator

The PDF will serve as a consultant to provide technical assistance to support Women of Colors and community stakeholders in carrying out community-engaged discovery process, the analysis of discovery data derived from the discovery, and the compilation of the final report and preparation of the public forum presentation.
The PDF will seek to ensure the integrity of any collaborative relationships in the data gathering clusters that will be composed of Women of Colors representatives and community stakeholders functioning as discovery partners.

- Prepares for and assists with facilitating monthly stakeholder meetings by helping to establish agendas and stakeholder presentations. (monthly stakeholder/Advisory Committee meetings)
- Leads collaborative establishment of timeline for completion of discovery clusters' task execution plans.
- Functions as technical point of contact for discovery clusters via Program Coordinator.
- Guides the formulation of the scope of the community-engaged discovery project.
- Provides comprehensive oversight and vetting of data collection implementation plans for community engaged discovery activities. Assists with developing community engaged discovery protocols and procedures.
- Monitors and reviews milestones with each phase of data collection to assure the execution of a synergistic community engaged data collection process.
- Conducts status review meetings following each phase of data collection. Provide follow-up and feedback.
- Works with the discovery clusters to assess themes from qualitative data (interviews, focus groups, open-ended survey questions and code transcripts).
- Performs appropriate literature searches in support of discovery process.
- Annotated review and write-up of shared discovery findings data from Saginaw County stakeholders.
- Consults with each community engaged discovery clusters to help ensure ethical conduct in all aspects of the discovery process.
- Leads authoring the final discovery report, conducts member checking, and finalizes editing for submission to MSU.

APPENDIX I: DESCRIPTIVE CODING LEGEND

	Code Acronym	Code Acronym Meaning	Code Description
1	CBHS	**C**omplexity of **B**ehavioral **H**ealth **S**ystem	Describes behavioral health care systemic challenges
2	CC	**C**ommunication **C**hallenges	Describes challenges in communicating effectively
3	CMP	**C**ultural **M**ismatch with **P**rovider	Describes feelings of cultural disconnect.
4	DC	**D**isempowered to **C**omplain	Describes feeling unempowered to criticize care
5	FS	**F**eelings of **S**hame	Describes fear of feelings of shame due to need for care
6	ID	**I**n **D**enial	Describes state of denial about the need for treatment
7	IP	**I**nconsistent **P**roviders	Describes frustration with inconsistency of provider care
8	ITP	**I**nflexible **T**reatment **P**rocess	Describes concerns about appropriateness of the treatment plan
9	LL	**L**ack of **L**istening	Describes feeling unheard or silenced
10	LPE	**L**ack of **P**rovider **E**mpathy	Describes lack of genuine care and relatability from provider
11	LPR	**L**ack of **P**rovider **R**espect	Describes lack of respect
12	LT	**L**ack of **T**ransportation	Describes transportation and accessibility challenges
13	MI	**M**istrust **I**ssues	Describes mistrust issues
14	OPD	**O**veruse of **P**rescription **D**rugs	Describes concerns about overuse of prescription drugs
15	PRP	**P**oor **R**apport with **P**rovider	Describes lack of connection or rapport with provider
16	PTE	**P**oor **T**reatment **E**xperience	Describes substandard treatment experience
17	RB	**R**eligious **B**eliefs	Describes religious beliefs that were relied upon rather than treatment
18	SS	**S**ocial **S**tigmatization	Describes fear of feelings of disgrace or great disapproval
19	WT	**W**aste of **T**ime	Describes feeling that time invested in seeking care was not worthwhile
20	XTR	e**XTR**a Code	Describes any extra code that does not fit into a priori code category

WOMEN OF COLORS

Racial Disparities in Behavioral Healthcare Project

1000 TUSCOLA STREET, SAGINAW MI 48607
(989) 737-9286
WWW.WOMENOFCOLORS.ORG