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MAINE CONSUMERS' THOUGHTS ON THE CERTIFIED COMMUNITY BEHAVIORAL HEALTH CLINIC (CCBHC) MODEL OF CARE

Prepared for the Co-Occurring
Collaborative Serving Maine

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EXECUTIVE SUMMARY

In the spring of 2022, the Maine Health Access Foundation awarded the Co-Occurring Collaborative Serving Maine (CCSME) funding to seek input from behavioral health consumers on a new model of care in Maine being designed and implemented by the Maine Department of Health and Human Services (DHHS). CCSME enlisted Hart Consulting to conduct surveys and focus groups with consumers and stakeholders across the state. The outreach objective was to understand consumer and stakeholder experiences with behavioral health services in Maine and seek their thoughts on the importance of the key components of the Certified Community Behavioral Health Clinic model (CCBHC).

The surveys were administered through a snowball sampling technique, where providers and associations emailed the survey invitations to their members. The survey was also used to recruit participants for three focus groups. Hart Consulting worked with a behavioral health provider to schedule one-on-one interviews with recent immigrants to Maine. In all 387 people participated in the survey research, 12 in the focus groups, and three in interviews. While the survey was translated into four languages (French, Somali, Spanish, and Simplified Chinese), there were no responses in non-English language options.

Survey Findings

Most Used Services Over the Past Year. The survey findings show that primary care physical health screenings were the used by the most respondents, followed by outpatient mental health, substance use services and screening and assessment services. The services used by the smallest number of respondents were community-based mental health care for military-connected families and psychiatric rehabilitation services.

Most Useful Services. According to survey respondents, outpatient mental health and substance use services, crisis services, and case management are the most useful services. However, respondents also reported the lowest levels of satisfaction with these services, indicating that the most necessary services also need the most improvement. Overall, however, respondents reported high levels of satisfaction with all services that are typically found in a CCBHC—74% of respondents were “satisfied” or “very satisfied” with the lowest-rated service (case management). It is important to note that survey respondents may or may not be served by a CCBHC.

Services Needed but Not Received. Outpatient mental health and substance use services, peer-to-peer and family-to-family support services, and treatment planning were the top three behavioral health services that survey respondents said they needed but had not received. In addition to behavioral health services, more than 50% of respondents need services related to food, transportation, housing, and training or education opportunities.

Thoughts on CCBHC Services. When asked to weigh in on the importance of the services provided by a typical CCBHC, respondents reported service accessibility was highly important: 89% indicated that receiving services within one week was important, 80% indicated that accessing services within 30 miles of home was important, and 80% indicated that 24/7 availability of crisis services was important.

Sources of Behavioral Health Information. Survey respondents expressed a preference for receiving behavioral health information via conversation with behavioral health providers, followed by conversation with a person in recovery and conversation with a medical care provider. They selected behavioral health providers' offices and websites as the best places to receive behavioral health information.

Focus Groups and Interviews

Across the board, focus group participants and interviewees identified lack of capacity, understaffing, and long wait times as major, interwoven challenges for people seeking behavioral health care in Maine. In addition, they emphasized how difficult it can be to navigate the behavioral health system—between paperwork, insurance rules, and lack of coordination among providers, it's easy to fall into “gaps” in the system. Several respondents highlighted the additional challenges facing people living in rural areas, or those for whom transportation and housing are not secure.

Like survey respondents, focus group participants identified prompt (within a week) access to services as a very important factor in receiving behavioral healthcare. They also underlined the importance of telehealth services, which can reduce barriers to getting help.

Focus group participants and interviewees want “person-centered” and trauma-informed care; they want to be seen as individuals and receive care that is tailored to them. They want providers to understand their unique circumstances and needs, involve them in treatment planning, and avoid labeling or stigmatizing them. Several people interviewed identified peer support as key to their own behavioral health care. They underlined the importance of being able to talk to someone without fear of the stigma or ignorance that they still experience with some health providers and the public.

Overall, participants stressed that information about behavioral health services should be presented in as many ways as possible, pointing out that when people need help, they should be able to find what they need in whatever way is available to them. But many identified conversations with others—whether providers or peers—as the way that they best received and processed information. This aligns with survey findings, which identified conversations with providers and peers as the top ways to receive information.

Several focus group participants recognized that Maine is trying to improve, or shared experiences of receiving better healthcare in Maine than they had in other states. In general, participants indicated that while the system is “stressed out” (as one participant put it) and needs major improvement, the case managers, care coordinators, and many clinicians are working hard to help people.

BACKGROUND

The Project

In the spring of 2022, Maine Health Access Foundation awarded the Co-Occurring Collaborative Serving Maine (CCSME) funding to seek input from behavioral health consumers on a new model of care in Maine being designed and implemented by the Maine Department of Health and Human Services (DHHS). CCSME enlisted Hart Consulting to conduct surveys and focus groups with consumers and stakeholders across the state. The objective of the outreach was to understand consumer and stakeholder experiences with behavioral health services in Maine and seek their thoughts on the importance of the key components of the Certified Community Based Health Care model (CCBHC).

Survey Research

Hart Consulting worked with CCSME, the Alliance for Addiction and Mental Health Services, Maine, Healthy Acadia, the Consumer Council System of Maine, Maine Department of Health and Human Services, and Market Decisions Research to create and share the online survey with people with lived experience, Black, Indigenous, People of Color (BIPOC) communities, Arab Americans, and those connected to the behavioral health sector. In total, 387 people participated in the online survey, including 28 BIPOC community members.

Focus Groups and Interviews

Hart Consulting staff worked with CCSME to design and implement three focus groups and three key informant interviews to probe more deeply on the questions from the online survey. The four audiences of interest included people with substance use disorder, those with experience with mental health services, family members of someone with experience with behavioral health services, and members of BIPOC populations with experience with mental health and/or substance use services.

In addition to the focus groups, Hart Consulting conducted three interviews between 11/29/22 and 12/2/22 via Zoom. Interviewees were members of families receiving services through a behavioral health provider and were recruited by the provider on behalf of the project

Limitations

The online survey depended on a snowball sample rather than a statistically valid random sample, and therefore offers a qualitative set of data. The data show interesting trends and observations of the respondents, but the findings cannot be generalizable to the population of people using behavioral health services in Maine.

The focus groups were important in probing into the findings from the online survey, however, focus groups provide qualitative, descriptive information and similar to the online survey cannot be generalizable to the population.

Further limitations are associated with the low participation rates of BIPOC and older people. We recommend future outreach focus solely on those populations to seek meaningful input for those populations.

This Report

This report shares a summary of the findings from the survey, focus groups, and interviews including verbatim quotes lightly edited for clarity. The focus group findings are grouped by theme, not by question, since shared themes emerged at different points in various group conversations and interviews. Quotes are shown in italics with quotation marks. Head nodding and statements of agreement are not repeated in this report but were considered in analyzing the data.

SURVEY FINDINGS

Survey Design and Administration

Hart Consulting worked with CCSME, the Alliance for Addiction and Mental Health Services, Maine, Healthy Acadia, the Consumer Council System of Maine, Maine Department of Health and Human Services, and Market Decisions Research to create and share the online survey with people with lived experience, Black, Indigenous, People of Color (BIPOC) communities, Arab Americans, and those connected to the behavioral health sector. The online survey was designed to answer the following questions:

- Which behavioral health services are important to consumers in Maine?
- What are consumers' general experiences with services?
- How do consumers assess the importance of the key components of the CCBHC model?

The survey was translated into four languages in addition to English: French, Somali, Spanish, and Simplified Chinese. There were no responses to any of the translated surveys. At the end of the survey, survey participants indicated their interest in engaging in a future online focus group and they had the opportunity to share their email to enter their name into a lottery for 10 people to win \$75 Amazon gift cards.

Survey partners and other stakeholder organizations shared the survey with potential respondents in a snowball sample approach from September 28 to November 3, 2022. Survey partners and behavioral health partners sent the survey to their members, listservs, and consumers. Partners known to have distributed the survey include CCSME, CCSM, Maine Alliance, Healthy Acadia, Kennebec Behavioral Health, Sweetser, Gateway, St Mary's, MaineHealth, National Council on Mental Wellbeing, and rural health coalitions in Western Maine.

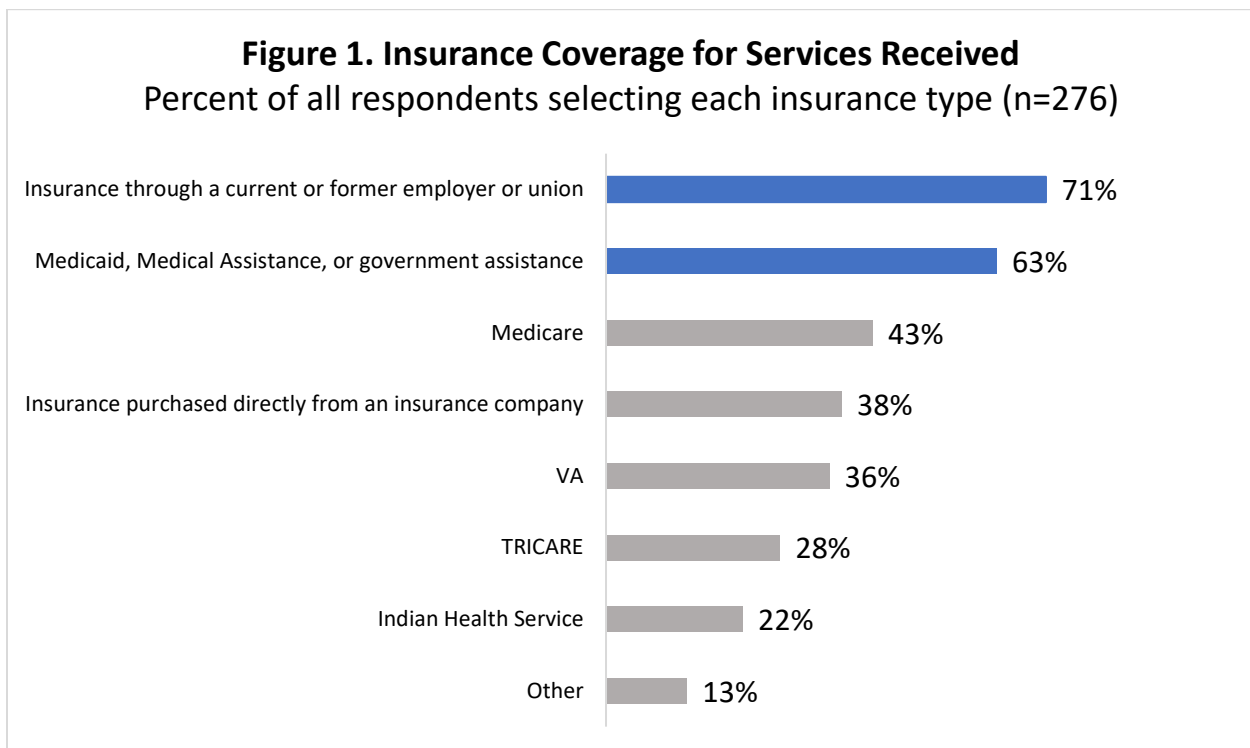
Respondent Profile

A total of 387 individuals initiated the survey, and the response rate varied by question. Of the 222 participants who answered the question about gender, 70% identified as women, 28% as men, and 2% as non-binary. Of the 270 respondents who provided their ages, more than 50% were between the ages of 27 and 45. See Table 1.

Table 1. Survey Respondents by Age (n=270)

Age	% Respondents Selecting
18-26	7%
27-35	30%
36-45	25%
46-55	19%
56-65	16%
66+	4%

Most respondents indicated that the services they received were covered by insurance through a current or former employer or union (71%) or by Medicaid, Medical Assistance, or government assistance (63%). Respondents could select more than one insurance type. See Figure 1.



Service Use

Primary care physical health screenings were the most commonly used service over the past year for both adults and children, with 180 respondents indicating that they had used this service over the past year, and 80 respondents indicating that a child in their care had used this service in the past year.

The next most common services used by both adults (reporting on themselves) and children were outpatient mental health and substance use services and screening and assessment. The

services used by the least number of respondents were community-based mental health care for military-connected families and psychiatric services.

Satisfaction with Services Found in CCBHCs

Respondents were asked about their satisfaction receiving a list of services typically found in a CCBHC care model. It is important to note that the respondents may or may not be served by a CCBHC. Overall, respondents reported high levels of satisfaction with all the services found in CCBHCs. Respondents were most satisfied with primary care physical health screenings and youth, adult, and family peer support. They were least satisfied with case management, crisis services, and outpatient mental health substance use services. However, even case management, the service with the lowest satisfaction rate, still had a 74% satisfaction rate.

Respondents could answer or skip questions about specific services. The largest number of respondents (279) answered the question about primary care physical health screenings, which was the most-used service. The smallest number of respondents (126) answered the question about community-based mental health care for military-connected families, the least-used service. See Table 2.

Table 2. Satisfaction with Services Offered in CCBHCs

Service	% Respondents Selecting “Very satisfied” or “Satisfied”
Primary Care Physical Health Screenings (n=279)	88%
Youth, Adult, and Family Peer Support (n=178)	84%
Treatment Planning (n=229)	79%
Community-Based Mental Health Care for Military-Connected Families (n=126)	79%
Screening and Assessment (n=249)	77%
Psychiatric Rehabilitation Services (n=157)	77%
Crisis Services (n=204)	75%
Outpatient Mental Health and Substance Use Services (n=259)	75%
Case Management (n=198)	74%

Most Helpful and Most Needed Services

Outpatient mental health and substance use services, crisis services, and case management were selected as the most helpful services. Respondents also reported the lowest levels of satisfaction with these services, suggesting that while these services are helpful, they are also perceived by respondents as the services needing the most improvement. See Table 3.

Table 3. Most Useful CCBHC Services (n=336)

Service	% Respondents Selecting Each Service as Among the Top Five Most Helpful
Outpatient Mental Health and Substance Use Services	70%
Treatment Planning	56%
Crisis Services	55%
Primary Care Physical Health Screenings	54%
Case Management	53%

Peer-to-peer and family-to-family support services and outpatient mental health and substance use services are the top services people need but have not received. Community-based health care for veterans, crisis services, and psychiatric services ranked the lowest on this list. These were also among the services that the fewest respondents had used. See Table 4.

Table 4. Needed Behavioral Health Services (n=255)

Service	% Respondents Selecting Each Service
Outpatient Mental Health and Substance Use Services	38%
Peer-to-Peer and Family-to-Family Support Services	38%
Treatment Planning	35%
Case Management	30%
Screening and Assessment	25%
Primary Care Physical Health Screenings	21%
Crisis Services	20%
Psychiatric Rehabilitation Services	20%
Community-Based Mental Health Care for Veterans	17%

In addition to behavioral health services, more than 50% of respondents selected food, transportation, housing, and training/education opportunities as needed services. See Table 5.

Table 5. Services Needed in Addition to Behavioral Health Services (n=255)

Service	% Respondents Selecting Each Service
Food	54%
Transportation	53%
Housing	52%
Training or education opportunities	52%
Health insurance	46%
Job opportunities	43%
Access to internet	28%

Themes from Open-Ended Responses to this Question

- Patient-centered approach
- Integrated approach
- Harm reduction support
- Inpatient detox
- Social services
- Financial support
- Community-based services
- Services and facilities specifically designed for children
- Respect
- Medical treatment
- Alumni program
- Respite care
- Alternative approaches
- Counseling
- Mental health club
- Day programs
- Housing
- Grief counseling

Select quotes:

- *“Social services programs for families over income guidelines but still experience poverty-stricken events due to unfortunate circumstances”*
- *“Children's services in the community”*
- *“actual medical treatment - not just assessments and physicals - and respect from the medical community (looking at you Central Maine Community Center)”*
- *“some type of alumni program that I could touch base as needed. Most other services require constant service and that is not what I need.”*
- *“Alternatives to any of the traditional approaches”*
- *“Services with an integrated patient centered approach”*

Meeting Behavioral Health Needs

Service accessibility was highly important to respondents. Receiving services within one week, accessing services within 30 miles of home, and 24/7 availability of services were selected as the most important factors by the greatest number of respondents. Receiving language interpretation services and receiving services from behavioral health providers who work with local law enforcement and corrections were the reported as important factors by the lowest number of respondents, but more than half of respondents still indicated that these services were important. See Table 6.

Table 6. Factors Needed to Meet Behavioral Health Needs (n=291-301)

Service	% Respondents Selecting “Very Important” or “Somewhat Important”
Receiving services within one week	89%
Accessing behavioral health services within 30 miles of home	80%
Having crisis services available 24 hours per day, 7 days per week	80%
Receiving care from providers who get input on their programs from boards that include people who have used behavioral health services	77%
Receiving care from providers who work with my family or others who support me	74%
Receiving services over the phone or computer	73%
Receiving services from behavioral health providers who work with your primary care provider	72%
Connecting you to transportation, housing, food, and other services	68%
Receiving services from behavioral health providers who are sensitive to different cultures	65%
Receiving services from behavioral health providers who work with local law enforcement and corrections, when appropriate	56%
Receiving language interpretation services	51%

Receiving Information About Services

Conversations with a behavioral health provider, a person in recovery, or a medical care provider were selected as the best ways to receive information on behavioral health services. A behavioral health provider’s office, a behavioral health provider’s website, or a peer recovery center were selected as the best places to receive service information.

Table 7. Best Ways to Receive Behavioral Health Information (n=286)

Way of Receiving Information	% Respondents Selecting Each Source
Conversation with a behavioral health care provider	63%
Conversation with person in recovery	49%
Conversation with a medical care provider	46%
Paper pamphlet	43%
Electronic pamphlet	42%
Video	37%

Table 8. Best Places to Receive Behavioral Health Information (n=286)

Way of Receiving Information	% Respondents Selecting Each Place
Behavioral health provider's office	57%
Behavioral health provider's website	53%
Peer Recovery Center	45%
Social media	42%
State of Maine's website	37%
Groups I belong to	30%
211	20%
988	12%
Other	8%

Final Thoughts Shared by Respondents

"Are there any other thoughts you would like to share?"

Themes from Open-Ended Responses to this Question

- Need better/more aftercare
- Need more holistic services
- Need different types of facilities
- Need facilities with more capacity
- Shortage of providers
- General barriers to accessing services (basic needs not met, transportation challenges)
- Care needs to be better coordinated among providers and other organizations
- Expensive
- Hard to access care
- Need better-trained providers
- Slow service/long wait times
- Too much burden on parents/family
- Need for open-minded treatment
- Need better medication management
- Stigma hurts patients
- Need patient advocates
- Lack of communication with family

Select responses:

- *"There's a frightening shortage of all types of medical providers in Maine, most especially for behavioral health. Most services that are provided are disjointed, complicated to access, and expensive. I was shocked to experience the level of chaos, lack of patient dignity, and absence of coordination between hospitals, PCPs, and behavioral health providers/services. It is also clear that the providers we Do have, our exhausted, overworked and in danger of burning out. There is a need for expanding the workforce, retaining those we have, and an orchestrated, collaborative approach to fully integrated care. Maine is a small a state (population wise), and we need to maximize all possible technology and innovative care models to meet the diverse needs of Mainers."*
- *"The system is slow - incomprehensively so. Our 13 yo was discharged from hospital and it took 4 mos to get a referral for outpt BH support. Hospitalization was woefully*

inadequate in giving kid any coping skills. She should have been in hospital for 6-8 weeks but was discharged after 5 days. Parents are left to carry too much."

- *"When organizations have unskilled screening staff to identify or triage where a patient show be seen, you are doing disservice to that person. Invest in the FRONT END with skilled staff."*
- *"Would love to have our educational system be the starting point for coping skills and for access to higher education be equitable to get more providers out there and for the support people such as peer support (that is CRITICAL and fills so many holes in gaps of care to be paid a livable wage that is more relevant to the critical role they fill."*
- *"My son has just been through hell and back. Until we landed at Barbara Bush there was no connected care. We had no support for follow-up, and providers who had egos that were too big. As parents, my husband and I were not consulted for the "story" of what had elapsed prior to hospitalization, nor were there any connections to his outside providers, despite my requesting this, and signing releases. The decisions that were made were just based on observation at that moment. My child has been hurt because of these practices."*
- *"Behavioral health providers need to be knowledgeable and skilled working with individuals across other disabilities, especially developmental disabilities such as autism"*
- *"Being open to naturopathic and homeopathic healthcare. Many people I know did not like the pushing of medications on them because of side effects. Better health management like understanding the need for healthy eating, rest and exercise and ways of managing stress before it turns to crisis. Programs which allow my loved ones to participate in exercise programs without the stigmatization of why they should."*
- *"I feel it is important for people to have advocates helping them navigate the mental health system, ER crisis situations and while in a psychiatric center. Under certain circumstances the person is not in a stable mindset and needs representation."*
- *"As a person in long-term recovery (35 years), I've had a lot of experience with knowing what works and what doesn't in terms of finding a provider who I feel comfortable working with. In Maine, my experience with the public behavioral health system was disappointing. In the short time I went to the local BH clinic, I had multiple counselors and prescribers, and I often had to provide the same personal information over and over again. With prescribers, I would have to have the same discussion about my medications and sometimes seemed to know more about the medications than the prescriber did. I would encourage Maine to do everything it can to support its providers, who work with the most difficult of individuals."*
- *"Maine desperately needs increased access to mental health services. There is an appalling lack of psychiatric providers, as well as psychologists. Also, I wish there was more privately run practices instead of conglomerates such as Northern Light Health and St. Joseph's. Make it more enticing for family practices to establish themselves here. Care provided by those providers is so much more personable."*

FOCUS GROUP FINDINGS

Focus Group Methods

Hart Consulting staff worked with CCSME to design and implement three focus groups and three key informant interviews to probe more deeply on the questions from the online survey. The four audiences of interest included people with substance use disorder, those with experience with mental health services, family members of someone with experience with behavioral health services, and members of BIPOC populations with experience with mental health and/or substance use services.

The research team recruited participants by email using the list of email addresses volunteered from the online survey. Interested participants completed an online form where they shared their first names, email addresses, and agreed to be recorded for notetaking and transcription purposes. Each participant received a \$25 Amazon gift card to thank them for their participation. See Table 9.

Table 9. Focus Groups by Date and Participation

Audience Experience with Behavioral Health Services	Date	Number of Participants
Substance Use Services	11/29/2022	6
Behavioral Health Services	11/30/2022	4
Family Members	12/1/2022	2

In addition to the focus groups, Hart Consulting conducted three interviews between 11/29/22 and 12/2/22 via Zoom. Interviewees were members of families receiving services through a behavioral health provider and were recruited by the provider on behalf of the project. Two of the three interviewees used an interpreter, cultural broker, and/or care coordinator. Participants shared their first names and agreed to be recorded for notetaking and transcription purposes; they each received a \$40 Walmart gift card to thank them for their participation.

CHALLENGES/BARRIERS

Not Enough Behavioral Health Services to Meet Demand

Throughout the focus groups and interviews, consumers described insufficient capacity in the behavioral health care sector to meet demand in Maine. Participants identified the interconnected challenges of long wait lists, lack of programs, lack of program capacity and understaffing as the top barriers to accessing behavioral health services in Maine. Both long-

and short-term wait times are challenges: people reported waiting more than 24 hours to be seen by crisis workers, and more than six months to access treatment programs and services.

“In my experience, wait times have been a major barrier. I’ve personally waited in the emergency room to be seen by a crisis worker for close to 50 hours.” [Families Focus Group]

“I waited seven months to get [into treatment]. That’s a long time to wait for someone who’s struggling on a daily basis to survive.” [Substance Use Services Focus Group]

“The wait times [for crisis services]...waiting in beds, waiting for beds, sitting in the hallways. I’ve left. I’ve gone in for help a number of times and spent 24 hours in a waiting area and [left] before treatment.” [Substance Use Services Focus Group]

“Even mental health services, there’s a lot of agencies that have really long wait lists and people are utilizing like crisis centers or inpatient stays more than, you know, they might, if they were able to get more access to services.” [Substance Use Services Focus Group]

“The most [worrying] thing at the beginning is just the waiting list until you get the services. Because, you know, the waiting list is very long for the intake. To get the intake, this takes a long time.” [Interview 3, via interpreter]

Lack of Programming

Participants described the lack of capacity in existing programs as driving the waitlists. They mentioned frustration accessing programs such as inpatient withdrawal management facilities, Community Recovery Residences, and crisis services, as well as case management and mental health counseling services. In addition, several participants identified specific programs they wish Maine would invest in, namely residential eating disorder programs, harm reduction programs, and Assertive Community Treatment (ACT).

“I don’t think there’s enough ACT [Assertive Community Treatment] teams available in Maine, which I think a lot of clients could benefit from but are unable to get. So instead they just get a regular case manager. And while that’s helpful, it’s not always what they would benefit from the best.” [Substance Use Services Focus Group]

[We need more] housing beds available for individuals that really struggle. Because even those, to get people into them when they need them is long wait times.” [Families Focus Group]

Staff Burnout

In addition to the lack of services, participants noted the harmful effects of understaffing: overloaded case managers and support staff, lack of trauma-informed clinicians, provider turnover, and burnout. One focus group member said that they hesitated to bring their concerns to case managers because they felt bad about further burdening them.

"I witness a lot of ...burnout from support staff. A lot of these individuals are in recovery themselves, so there's a really difficult balance. They come in and they very willingly wear many hats, but very quickly things are getting overlooked that can result in major hiccups for people." [Substance Use Services Focus Group]

"My big [barrier], especially with counseling, has been provider turnover. You just get used to somebody or get to the point where you can start to open up, and then they're leaving. I actually don't do counseling anymore. I'm very hesitant about even trying counseling, just because I've had that happen numerous times. I generally say I have counselor trauma." [Substance Use Services Focus Group]

Lack of Coordination Across Services

Participants expressed frustration with the lack of coordination among different behavioral health agencies and providers, sharing that delays and being shuffled among levels of care made them feel like they and others were falling through gaps in the system. They noted that provider quality can vary substantially, and that some providers seem to prioritize paperwork over patient connection, especially in crisis services.

"I feel that in general the mental health system in Maine is a very broken system. There are parts of it that function and work really well, but as a whole it's not a great system. A lot of people fall through the cracks." [Families Focus Group]

"I think a lot of what has hindered my recovery is the back and forth between programs, waiting lists, being moved between levels of care. Sometimes it has felt kind of careless, like just being this ping-pong ball between different programs, all of [which] had their own problems." [Substance Use Services Focus Group]

"In general, people will have providers, but unless they're within the same agency, and sometimes even then, there's not a lot of coordinating. I think if people were coordinating about an individual's care a little better, then things might go smoother... As a provider now, that's something I see a lot of." [Substance Use Services Focus Group]

Logistical Barriers Include Housing, Transportation, and Insurance

In addition, participants highlighted the logistical barriers to accessing care, saying that it's very difficult to navigate the system, especially for individuals who struggle with access to housing, transportation (especially in rural areas), or insurance. Finding care that's available, accessible, affordable, and fits into a work schedule (in the case of outpatient treatment) can be an enormous challenge.

"When it comes to transportation, especially in the more rural parts of Maine, I think people really struggle to even get in the doors to see someone and explain what their experiences are, whether physical, emotional, mental, or otherwise." [Families Focus Group]

"[Are] there any services for somebody to come and take my wife or my kid to a dentist or to a doctor? Because this is a big issue. I cannot leave my class to go and take my son or my daughter to a dentist or doctor. Transportation [is a] problem." [Interview]

"I personally haven't accessed services in about a year or so now, because for so long I have actually been unemployed, and insurance is mostly tied to employment; for me, anyhow, that's how it's been. It's been very difficult to receive services. I would start to see a therapist and then maybe my employment would change, and I wouldn't be able to qualify for coverage anymore. I've experienced how billing and insurance get in the way of receiving services." [Families Focus Group]

IMPORTANT FACTORS IN ACCESSING HEALTHCARE

Shortened Wait Times for Services are Most Important

Participants emphasized that all factors of the CCBHC model of care—from quick access to care to culturally sensitive treatment—were important in serving people with behavioral health needs. However, access to services within a week and access to telehealth services were priority factors for most participants. One person noted that when someone decides they are ready to address their behavioral health needs, it is important that treatment be available quickly; any long delay reduces the chances that they will follow through on seeking help.

"I think that immediate access is crucial to getting people into long term recovery and getting them back on their feet." [Substance Use Services Focus Group]

"As easy as it is to make an impulse decision to get help, it's very easy for someone to wait a couple days and essentially change their mind. I think picking up that phone or going to that center or realizing that you want the assistance—those first couple days

or even hours are the most important. I think [rapid] service time and turnaround, the additional contact is huge.” [Substance Use Services Focus Group]

Telehealth is a Good Option, But Not a Replacement for In-Person Treatment

For many people, telehealth services reduce barriers to treatment, particularly for follow-up care. Still, some people emphasized that in-person sessions, especially when trying to build rapport with a provider, remain essential at the beginning of treatment, before transitioning to Zoom or phone sessions.

“[Telehealth] has improved the consistency with which I've been able to maintain therapy appointments and not have to cancel because of things that aren't even necessarily behavioral health. If I'm having a day that's been particularly stressful or I'm very tired, rather than layering on the drive to the office, the being in the office space, the driving back home, I can log on.” [Mental Health Services Focus Group]

“[Telehealth is] important. I agree a hundred percent with that. But for me, I've found it hard to find somebody who's willing to meet in person. And as far as meeting somebody new and building a rapport with somebody new, I need in-person contact. I'm fine doing Zoom therapy after I have a rapport with somebody. But the balance is important.” [Mental Health Services Focus Group]

NEEDS IDENTIFIED BY PARTICIPANTS

Person-Centered Care is Important

Focus group participants and interviewees want to be treated as individuals and have their care focused on their needs. They want access to programs, counseling, and treatment plans tailored to their needs and providers who can address their specific behavioral health concerns. Several participants reported negative past experiences with counseling that felt “cookie cutter” and standardized treatment plans that were medication-heavy and made them feel “objectified.” People agreed that they wanted to be empowered to have a voice in their own treatment planning.

“I think that the patient or the client needs to have more of a part in [treatment planning]. We need to be more involved, instead of somebody saying, ‘This is what we're doing, here you go.’ That feels very abrasive. There's not a whole lot of, ‘What do you think would work for you?’” [Substance Use Services Focus Group]

“There's a lack of peer support or alternative models. There's a big focus on clinical medicalization, without exploring other options. I know peer support's getting bigger

in the state, but I think more and more resources [are going] towards increased medicalization and clinical treatment, and not enough towards recovery, housing, and peer support, or those even being considered in treatment planning.” [Substance Use Services Focus Group]

Consumers Want to Feel Respected and Not Stigmatized by Health Care Providers

Participants also shared frustration with the lack of trauma-informed services available in the state, and expressed that providers are sometimes ignorant or insensitive to how trauma or disabilities can be interwoven or affect how patients respond to treatment. They want health providers across the board—not only behavioral health providers—to be culturally sensitive and avoid further stigmatizing people with behavioral health needs.

“What I really would push for is trauma-informed practitioners. [My sister and I have] clusters of disorders or conditions. So, it's difficult to stay with a practitioner long term. And it seems like some of the harder and more trauma-based concerns that people may have, it's difficult to get [into therapy] and work with.” [Families Focus Group]

“I have had to very explicitly seek out [culturally sensitive treatment] and learn how to ask questions in order to get it. And the people who are able to do so are few and far between. For me and for what my particular needs are, it doesn't come generally or generically within the behavioral health context at all. That hasn't been my personal or indirect experience amongst the people that I have interactions with. It's not just cultural in terms of race and ethnicity, it's also across disability that people within the behavioral health system are not culturally sensitive to the experiences of people who have other disabilities that affect their lived everyday experience and how they navigate the community.” [Mental Health Services Focus Group]

“It seems that there's still a lot of stigma in Maine. Stigma from providers that are not mental health providers but are healthcare providers. Like doctors and case managers and some other people that aren't necessarily plugged into the mental health side of it, but they're still healthcare providers. You'd think those people wouldn't have that, but they do.” [Mental Health Services Focus Group]

Consumers Want More Support Services

Collectively, participants underscored the need for expanded or additional services for people with behavioral health needs. Several participants advocated for better aftercare and transition support after crisis; well-structured peer support opportunities; housing support; and behavioral health education for employers and community members. In every focus group and interview, people emphasized the importance of meeting the basic needs of people seeking

treatment. As one person put it, “You can't focus on developing tools to better cope with your experiences and all the rest if your basic food and shelter needs aren't met.”

“Peer support is what was life changing for me, that connection. There's so much [opportunity] when you harness the community to support the community. That's how we build healthy communities.” [Substance Use Services Focus Group]

“My goal is to change my home. This is my real problem. I need to change my home and that makes me very depressed. I think this is the most important goal for me that would affect my mental health and the whole family's mental health. It's been four years for me trying to change, and I'm just on the waiting list. I hope that I get this help because that would also help the kids.” [Interview]

A huge challenge to accessing services is housing. I work with a lot of people who are unhoused, and I can get all the therapy they need and all the therapy they want and all the supports that they need. But if they live in a tent, their basic needs aren't even met. You can't focus on developing tools to better cope with your experiences and all the rest if your basic food and shelter needs aren't met.” [Mental Health Services Focus Group]

Consumers Need Culturally Responsive Care

Both interviewees and focus group participants emphasized the importance of holistic, culturally and linguistically responsive care.

The importance of holistic care emerged as a theme in all three interviews conducted with Maine residents who immigrated here from other countries. One interviewee highlighted how important it has been for their case manager to help the family access services they need. Two others expressed concerns about housing—one shared that they were living in a space too small for their family, and another mentioned that their rent is increasing, and it is hard to find an affordable apartment where they live. Transportation support also came up in all three interviews. Two people shared that it is important to them to receive care at home, and one wondered about whether there are any services that could provide transportation to medical appointments.

It is worth noting that interpreters provided interpretation services during two of these three interviews, and one of the interviewees shared that they do not know how to access interpretive services outside of the behavioral health agency's cultural brokerage and interpretive services. While the third interviewee spoke English, they noted that immediate family members rely on interpretive services at appointments. As one interviewee put it, it

is “[one] hundred percent” important for their family to receive language interpretation services.

While relatively few focus group participants felt that they had personally needed culturally responsive care, they see a need for culturally and linguistically responsive care in Maine. One pointed out that more language skills and training opportunities—for languages including Spanish and ASL—would be beneficial. Another participant had received care through Wabanaki Health and Wellness and was quick to describe the benefits of the agency’s holistic approach.

“The most important thing I want to say is that the first and [biggest] barrier is about language.” [Interview 1, via interpreter]

“I can tell you through Wabanaki Health and Wellness, I have all of that [holistic care]. I have four people on my team talk to me every day. So I think everybody should have the same thing.” [Mental Health Services Focus Group]

“I’m trying to serve as a bridge between the family and the clinician, who is from another culture. Trying to explain some words that are not in our culture. It’s new because this kind of service is not back home. It’s very new. That’s why the clinician needs to work with a cultural broker to help her or him to understand the context, the cultural context, to provide an efficient service to our clients.” [Interview 1 interpreter/cultural broker]

BEST WAYS TO RECEIVE INFORMATION ABOUT BEHAVIORAL HEALTH SERVICES

Behavioral Health Information Should be Shared in Many Ways

Across the board, people confirmed the importance of sharing information about behavioral health services in as many ways as possible. In-person conversations—whether with a provider or a peer—came up repeatedly as an effective strategy, especially because it can be hard for people who are struggling to hold onto phone numbers or pamphlets or access the internet. Several participants said that because people process information in different ways, it is crucial to present it in as many ways as possible. One person said that there should be “no wrong door”—no matter how you ask for information, you should be able to receive it. A few people also expressed that a centralized database for information—on the Maine.gov website or elsewhere—could be helpful to providers and patients.

“As someone who is in treatment and a person who has helped other people access treatment in the past, I think peer to peer is the most effective way to reach someone who’s struggling. People who have struggled with the same issues can best relate, and

that's who I think people that are struggling are going to listen to the best.” [Substance Use Services Focus Group]

MAINE IS DOING A BETTER JOB THAN OTHER PLACES

Several participants shared that while Maine’s behavioral health system overall desperately needs improvement, certain agencies and systems have been improving access and quality of care. Most people were quick to acknowledge that many individual providers—case managers, support staff, care coordinators, and clinicians—are doing their best to help people despite systemic limitations. A few people said that their experiences with behavioral health services in Maine, while imperfect, surpassed experiences in other places, including Washington, D.C. and Canada. Two had relocated to Maine specifically for access to programs unavailable to them elsewhere.

“On the whole, from what I'm hearing from people who are currently accessing the Maine mental health system, it seems like in some agencies and in some places there's quite a bit [of improvement] when it comes to how people can receive services, the wait times aren't as long and the quality of care might be a bit more personalized, which is great.” [Families Focus Group]

Reflections on the Outreach Process

Throughout the outreach process, the research team took steps to translate surveys, invite BIPOC participation, and pose direct invitations for participation and inclusion. Our experience was that the snowball sample method used in the online survey was not successful in reaching many BIPOC participants and the email focus group invitation was not successful, either. Working directly with a behavioral health agency’s case workers was successful, but the participants’ show rate for the interviews was low.