THE STATE OF BEHAVIORAL HEALTH CARE IN MASSACHUSETTS

PERCEPTIONS OF PERSONS WITH LIVED EXPERIENCE AND PROVIDERS
FOCUS GROUP REPORT
Methodology
HCFA conducted a total of 6 focus groups with consumers and behavioral health providers. Two focus group discussion guides (a uniform set of open-ended questions and discussion prompts) were developed to probe for participants' knowledge, attitudes, and experiences in receiving or providing behavioral health care in Massachusetts. The focus groups were an hour and a half in length and were conducted over the internet using Go To Webinar, a technology that facilitates online conference calls and seminars. Participants were recruited via electronic outreach to Facebook, Craigslist, HCFA website and distribution lists as well as through partners of HCFA throughout the state. The focus groups took place October-November 2016 at various times to suit participant needs. $25 Amazon gift cards were provided to all participants.

Four focus groups were held for people with lived experience. While 55 were recruited, a total of 30 consumers participated, with 3 individuals representing a family member. Consumers represented a wide range of locations as shown on the map in green: twelve were from the Boston area, six were from Central Massachusetts, four from the South Shore, four from the North Shore, three from Western Massachusetts and one from Cape Cod. Twenty-six consumers were white, one was black and one was Asian. Two consumers were of Hispanic or Latino/a origin. Nineteen consumers were female and nine were male; one person identified as transgender. All consumers had sought care for mental health and six had additionally sought care for substance use disorders. (See Appendix for additional details.)

Two focus groups for mental health/substance use providers were conducted. 24 were recruited, and 12 providers ended up participating. There were seven clinical social workers, one nurse, one clinical psychologist and three psychiatrists. Locations of practice included the following regions in Massachusetts: Boston, Worcester, Framingham, South Shore, Lexington and Springfield. These locations represent a wide range of geographical locations as shown on the map in blue. Types of practice settings included solo and group practices, community health centers, community mental health centers and a women’s shelter.

Ten of the providers were white, one was black and one was mixed race. Seven accepted both MassHealth as well as in-network private insurance; two accepted only MassHealth; one accepted only in-network private insurance and three did not accept any insurance, taking only private pay clients. Eight providers were female and four
were male; no one identified as transgender. All providers treated mental health issues, and eight also treated substance use. (See Appendix for additional details.)

Consumers and providers completed an online “screener” questionnaire and, once they qualified, were asked to provide consent through an electronic “signature.” The consent procedure was explained at the beginning of each focus group, and no last names were used during the groups. All discussions were audio recorded and transcribed for analysis.

The analysis involved a combination of independent and collaborative analysis. Two members of the coding team generated a code book consisting of descriptive and interpretive concepts identified during review of the open-ended data. The team went through an iterative process of open coding of a subset of the transcripts. Each person independently developed codes capturing their interpretation of the underlying meaning of participant comments. After each team member completed their coding of a sub-topic, the team met to review the coding, mutually agreed to codes and their definitions, and reached consensus about how to apply the created codes to the data. This process of independent coding continued, and was followed by consensus work until all groups were coded. See Appendix for frequency of themes by group type.
Executive Summary

In 2016-17, HCFA conducted an environmental scan of the state of behavioral health care in Massachusetts. As part of this assessment, HCFA conducted focus groups with people with lived experience (consumers) and providers to better understand coverage for, and access to, care for people with mental health and/or substance use concerns. A total of 42 people participated in 6 “virtual” focus groups in Fall 2016. Themes were remarkably consistent among consumers and providers.

CONSUMER THEMES

During the four focus groups with people with lived experience, discussion focused around five main themes.

CHALLENGES OBTAINING CARE FOR MENTAL HEALTH AND/OR SUBSTANCE USE CONCERNS

Consumers discussed numerous challenges around getting care for mental health and substance use issues. Discussion focused on difficulties finding a provider covered by their insurance plan, with an easy-to-access location, available appointments, and appropriate expertise for particular behavioral health conditions. Many noted that the length of time it takes to find a provider was especially debilitating, especially during a behavioral health crisis.

Many noted several important qualities they seek in a provider beyond availability, although some found these qualities difficult to define. Many discussed the importance of “patient-centered” care including respect, recognition of consumer “expertise,” patient-provider collaboration and shared decision-making.

Finally, consumers discussed their current dissatisfaction with care, including hospital “boarding,” the debilitating impact of waitlists, the lack of available “beds,” and other concerns about quality and care coordination.

CHALLENGES USING HEALTH INSURANCE FOR BEHAVIORAL HEALTH CARE

Consumers discussed numerous challenges with their health insurance plans. Discussion focused around the sense that insurance companies had too much influence on their care, often dictating care rather than their physicians, therapists or counselors. Moreover, communication with their insurance company was often difficult, leading to challenges understanding printed materials about benefits, confusion about how benefits were applied, as well as getting accurate information about participating providers. Many felt overwhelmed with the requirements of being an effective advocate on their own behalf. Finally, consumers discussed the barriers they found in choosing an appropriate health insurance plan that could meet their behavioral health needs.
CHALLENGES IN MANAGING COSTS

Many consumers shared their struggles paying for care and medication, even though almost all had insurance. Common themes included excessive out-of-pocket costs; frustration and confusion around costs and learning about coverage problems at challenging times; and the surprise at lack of cost transparency. Many discussed their decisions to get care outside of their insurance plan’s network.

PERCEPTION OF FAIRNESS AND EQUITY IN BEHAVIORAL HEALTH CARE

Overwhelmingly, consumers perceived a profound inequity in how behavioral health problems are treated as compared to physical health care. Whether these experiences indicate potential violations of state and federal parity laws, their experiences suggest it is still more difficult to access mental health or substance use treatment than other types of health care.

STIGMA’S EFFECT ON BEHAVIORAL HEALTH CARE

Stigma was noted to create many barriers in care-seeking behaviors. This includes lack of disclosures to primary care providers, friends and colleagues, as well as avoidance in seeking care.

PROVIDER THEMES

Across the two focus groups with providers, discussion focused around six main themes.

CHALLENGES PROVIDING CARE IN AN OVERBURDENED SYSTEM

Whether in an inpatient setting or outpatient setting, providers discussed several significant barriers to care for their patients, including waitlists and other delays in care, hospital boarding and inappropriate emergency room use. Providers discussed the limited availability of outpatient services in general, challenges in making appropriate referrals, and the lack of availability, delays and discontinuity of care for particular populations. Discussion also focused on the impact of an overburdened system on quality of care.

CHALLENGES PROVIDING CARE UNDER INSURANCE/MASSHEALTH PLANS

Across both focus groups, providers felt that working with insurance companies made the delivery of care difficult and in many cases, unsustainable. Providers discussed insurance plans’ interference with treatment plans and medications; demands of additional time burdens needed for appeals and authorizations, which is uncompensated; and the impact of low reimbursement rates, especially for their MassHealth patients. Many providers discussed an obligation to advocate on the part of their patients, but were concerned about the required time burden. A number of providers felt that in order to stay “in business,” providers are deciding to discontinue participation in insurance panels altogether.
THE “SYSTEM” DOESN’T SERVE THE NEEDS OF CONSUMERS with BEHAVIORAL HEALTH NEEDS

Several providers discussed the need for better integration and coordination of care, as well as improved quality of care. Others mentioned their frustration with the lack of communication with other providers and even hospitals. A few providers believed that the current system is providing poor quality of care for people with behavioral health needs.

INCONSEQUENTIAL IMPACT OF PARITY LAWS ON BEHAVIORAL HEALTH CARE

During each group, questions were asked about state and Federal Parity laws and their impact on care. While most providers had some awareness of and knowledge about parity laws, most felt that in practice, parity laws have had little effect on ensuring equal access to care. In addition, few providers felt that consumer knowledge about these laws would help them in challenging insurance company denials.

STIGMA HAS A SIGNIFICANT EFFECT ON DELIVERY OF BEHAVIORAL HEALTH CARE

While providers did not discuss stigma in depth, they mentioned it as having a great effect on care-seeking behaviors and the overall dysfunctionality of the behavioral health care system.

VISION FOR A MORE EFFECTIVE AND EFFICIENT BEHAVIORAL HEALTH CARE SYSTEM

Both focus groups ended with a request for providers to envision a better system for behavioral health care in the state. A few providers mentioned insurance company transparency, coordination of care, use of psychiatric preventative medicine, and the promise of behavioral health integration in Accountable Care Organizations.
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CONSUMER THEME 1: CHALLENGES OBTAINING CARE FOR MENTAL HEALTH OR SUBSTANCE USE CONCERNS

Consumer focus group participants discussed many challenges around getting care for mental health and substance use disorders. First, they noted numerous challenges in finding an available provider covered by their insurance plan. Other issues concerned location, schedule availability, and language access. Some discussed challenges in finding appropriate expertise for particular behavioral health conditions. The length of time it takes to find a provider could be especially debilitating. The difficulties of these efforts are all compounded by the challenges in finding providers during a behavioral health crisis. It is interesting to note, however, that a few consumers talked about their ease in finding providers for mental health and substance use disorders.

Many consumers noted several important qualities they seek in a provider, although some found these qualities difficult to define. Many discussed aspects of “Patient-Centeredness” in care, including: the feeling of provider respect, provider recognition that the consumer is expert in his or her own mental health, provider recognition of treatment preferences, accounts of past treatment experiences, and how well the information about treatment is shared between the provider and consumer. Collaboration and shared decision making was also noted as an important element of care.

Finally, consumers discussed their dissatisfaction with behavioral health care, including hospital “boarding,” ineffective use of the emergency room, the debilitating impact of waitlists, the lack of available “beds,” and other concerns about quality and care coordination.

I. Challenges finding providers

Most consumers discussed numerous challenges in finding an available provider that takes their insurance.

I recently relocated … and actually found great difficulty in trying to find a therapist who would accept my insurances which discouraged me from trying to find a therapist. …it was a nightmare

[I had a list of] some really great therapists, both private practice and community based, and of course the almighty first question is what type of insurance do you have. And despite the fact that I have insurance, I was told 100% of the time, we don’t take YOUR insurance.

…[I]t’s not really been a problem finding a provider, a physician or a doctor, it’s been an issue if do they take my insurance and for some reason it just always seemed that the type of specialist that I needed, in some kind of way I wasn’t able to use my insurance so I would usually have to self-pay.
... if you want to go to the [provider] that you like, then that might not be covered by your health insurance so you have to stick to whatever they pay for because you don’t have the thousands of dollars to go see the one that you like.

One consumer discussed the challenges in finding a provider who will take MassHealth and Medicare.

...there’s not that much out there and I’m ... on Medicare and MassHealth and psychiatrists don’t really like that type of insurance unless they’re working in a clinic.

Sometimes inadequate insurance coverage meant that consumers didn’t seek care at all.

I haven’t seeked long-term treatment for a while...due to chronic relapses and um just not being able to go to the places that, to some of the places I used to be able to go, like because my insurance wouldn’t cover it...

... I was seeing a psychiatrist for a long time and then I got new insurance through work and basically, uh, I got the ‘ok’ from her that I didn’t need to see her anymore mostly because she thought I was fine and I told her I couldn’t afford deductibles anymore.

The need for referrals to find an appropriate provider also presents a challenge.

Where first how difficult it is to get the referral, and is there a specific place that you can only get a referral? There are places that it’s only around where you live, there’s insurance, that it’s only the doctors under that insurance. There’s patients that need a doctor in another language that wouldn’t be covered. There’s patients that need a woman doctor or a male doctor and that referral process and how much it’s going to cover and is it out of your plan or if it isn’t that is very important ‘cause it all depends on your referral how much money you’re going to end up paying.

Finding appropriate providers
Some discussed particular challenges in finding appropriate expertise for a behavioral health issue.

I mean there’s not someone who is familiar with cases like mine on every corner or even in every state. I do keep seeking help but when I don’t find anything that fits my insurance or is somebody who has a good reputation, knows about the types of problems that I have then I might just stick with the person that I have.

You go to the website of … your insurance company and you get a list of a bunch of providers... You have hours that you can go. If they do have hours, then you pair it down to somebody who specializes in ADHD. [Then you have to] cut out like 95% of them and then the rest don’t have hours that we can go ...

It is difficult to find a provider for young adolescents. After school hours are typically filled or unavailable, or they don’t take insurance or are not taking new patients.
Some relied on trusted referrals to find a provider.

I also look for connection to other providers that I trust – this provider says ‘oh, I’ve worked with them at this place’ or ‘I’ve had patients that have seen them and really liked them’ … that’s a big plus for me.

Finding the “right” provider: Desired qualities

Many consumers found it difficult to describe the exact qualities they seek in a mental health or substance use provider. Several discussed the need for a connection or “click.”

So, it’s very difficult to seek care and do all of the things you need to do to find a qualified physician who takes your insurance which is hard enough … It’s very difficult to find people who are good, who you connect with because it’s a very personal relationship.

… it’s almost like… I don’t know, finding a friend or, you know, finding the right job or the right partner in life that, you know, that they’re… what might be right for one person might not be right for the other person. So, it’s really about making that match.

You kind of have to see if your personalities mesh well and if you’re going towards any goals or if there’s not any progress then you kind of know it’s not a good fit.

… They have to connect with you on a more personal level than, say, your primary care which is mechanical. You go in, they take your blood pressure, you take your shot or whatever. But you have to really open up to your psychiatrist and so it has to be someone that you relate to on a certain level. I kind of said ineffable ‘cause it’s hard to sort of put your finger on it exactly what makes a good match.

I’ve seen a fair number of therapists …and out of maybe like the 5 or 6 I’ve gone through, only one of them has been actually a good fit for me …and I’m not entirely sure what made her such a better fit than the others, I know that the others were very nice and I’m sure they were very capable and competent, but I just, I wasn’t getting anything out of it.

Having a sense of connection that’s kind of ineffable, it’s real personal to everybody. And also the communication style is very important … flexibility in their communication style is also very important, being able to share… and use different styles of interviewing and relating to people. So it’s like connection and communication combined I guess.

We go into several and they just don’t connect with my son so there’s no point of going if he’s not getting anything out of it.

For me it’s a goodness of fit issue which isn’t something you can measure or something you can come down to certain criteria. It’s hard but, for me, I think a person that I see as a clinician has to have a strong personality but also having to be caring and able to work with me with coping skills. Also, I take a long time for things to kind of settle in and for me to make decisions so not putting too much pressure on me to make a decision in a single session or in a week or something
... the first match might not be the right match, and it might take a couple of different trials with different therapists, but that doesn’t seem to be an option in the greater Boston area. It’s just like, this is who you’re assigned to, this is when you’re going to show up, and that’s the end of the story. And if not, then find another agency.

Consumers discussed the importance of feeling respected, being recognized as an expert in their own behavioral health care, provider recognition of treatment preferences, accounts of past treatment experiences, and shared decision-making between consumer and provider.

The type of therapy, like, I know what works for me. I mean I’m the expert on me, not the provider, so to tell me that I’m going to get, for example, cognitive behavioral therapy, I know that doesn’t work with me. I know what works for me. So work with me, don’t tell me what you’re gonna do. So, to have that communication and partnership.

Yea, definitely a connection, and for the provider to, and I’m just speaking about myself, but I’m the expert on me, you’re not, I’m the one that’s living this life and have these concerns, so to really, not just listen but hear what I’m saying.

One of my favorite things about my psychopharmacologist is that he does research and he works in a clinical setting so I feel like he just... and I never questioned how much he knows and his level of expertise but also not feel disconnected from [him]... And ... just someone who’s sort of has similar life view, an outlook for me and similar sense of humor and it doesn’t feel like... it feels more like we’re partners in figuring out what’s going on with me rather than doctor/patient, somebody’s in charge and somebody’s not.

I’ve been to ... several therapists over the years... and you talk to them about what your issues are, and typically what I find is that they kind of identify what they think your issue is, and then they focus on that. And I understand that they are the professional and they might have a roundabout way of helping you with your issue, but it rarely turns into that, it’s like they just kind of interpret um, your quote unquote problem as being something different or something that they can manage or something that’s in their realm of management, so that’s what they focus on [not what I need].

**How the search burdens consumers**

A few consumers noted the unique challenges in finding providers during a crisis, often compounded by the length of time the search takes.

If you’re in the deep depression, you’re in a pit and the last thing you want to do is find ... help.

I think that the healthcare system is not set up particularly well to manage mental health and behavioral health in that the two things that I deal with and the two things that most of my clients deal with being ADHD and depression and anxiety are in and of themselves barriers to care. So, it’s very difficult to seek care and do all of the things you need to do to find a qualified physician.
who takes your insurance which is hard enough but it's hard to do that when you're suffering from untreated ADD or depression and anxiety, and then you compound the fact that if you can't find someone who takes your insurance it can often be prohibitively expensive.

When someone is ready to go inpatient and they have a drug/alcohol and a mental health problem... that's very hard to get somebody in... So often time the window of opportunity to really grab somebody when they're motivated closes. ... I had a hard time finding a bed when I was really ready to go. You have to wait a week for that. It dampens your motivation...

... [you get a list and] they might all not be accepting new patients. Or they might all not take your insurance. And then you're back to square one so it's much harder and takes much longer.

Finally, consumers mentioned other challenges such as lack of consumer knowledge, provider location, schedule availability, and language access.

I think access is a big issue ... I run like twelve recovery groups a week and there's a lot of people, either because of their socioeconomic status or different things, can't really access or don't know how to access mental health care and they end up going through the public sector and there's all this gate-keeping...

Scheduling. Not everybody is available Monday through Friday 9 to 5. So there has to be some flexibility in terms of evening hours or some kind of weekend hours. So that people can access the care.

... I had to go out and search by hand and... go to all these various places, find them, park them, find the location and the building and it was like a real challenge to do all that. You know, 'cause taking time off of work or arranging it throughout the work schedule. I was working then. Since then I've actually lost my job because of my condition.

When I worked closer to the city, it's just easier to find ..., treatment ...

I've definitely had problems locating eating disorder-specific clinicians who I trust so I actually do travel quite a bit [to get care].

... I was seeking help for a family member [who] didn’t speak English so that was a difficult thing to navigate through to find providers who were able to communicate directly without an interpreter.

Interestingly, a few talked about the relative ease of finding providers for mental health and substance use.

But as far as like people talking about getting help as far as psychiatry, I mean, it's a matter of looking around and then looking in the phone book but, uh, around this area, just making a call and within a matter of a week, one week, two weeks you get an appointment to see a psychiatrist any time.

Yeah, it’s, I mean if you look in the phone book, there are places that take MassHealth and Medicare and like I said, if it doesn’t go through Medicare, it will be covered by MassHealth in places that I've known in this area.
One consumer discussed the important network of care found in his area.

I’m from the Brockton/Fall River area and to access psychiatry help and clinical, social workers and stuff like that is very, very, very easy over here and there’s... there are... are a lot of psychiatry doctors, there’s a lot of clinical social workers that refer you to psychiatrists in this area... .... There’s acute care and there’s chronic care. [With acute care] ... they take you for five days, they release. But after that there are programs ...you can go to ... houses ... where you’re supervised ... the places that I work with... they’ll refer you to a place or take an [Intensive Outpatient Treatment] where you have to stay there for 5-6 hours and discuss what you have to do. But in this area, I mean, it’s very, very, very, very simple. I mean, you form a network and that network ... helps you.

II. Dissatisfaction with Care: Inpatient Care

Hospital boarding and emergency room use
Ineffective use of emergency room care and hospital “boarding” was noted as a critical quality of care issue for people in crisis.

... I had a hard time accessing places. It’s finding a bed is a hard thing to do. ...that’s very hard to get somebody in when they need to go in [so instead they go to] an emergency room.

Well, as a mother, it was hard to see and hard to look at ... We had difficulty finding a bed in the emergency room. For several days, I called [my insurance company] and said my son is in the emergency room being watched by a guard at, you know... he can’t shower, he hasn’t... He needs a bed. And it still took time, it took a lot of time ...so it was very frustrating on him.

I hear from families on listservs that there are no beds, and they’re waiting in emergency rooms or they are sent out of state.

... Mental health ... can be just as emergent as a physical problem if somebody’s ...possibly suicidal. I think it’s harder to get... it’s the access, there’s no real “mental emergency room” where you can connect with people who really know what they’re doing in terms of substance abuse. And in Boston now, there’s a new job that ...[goes] to emergency rooms when somebody OD’s or something like that and connects with them right away, which usually it didn’t in the emergency room. I was put in a hallway or a room by myself which was very uncomfortable.

Unavailable care: no “beds”
Several consumers discussed the shortage of available placements for inpatient care as a problem for both mental health and substance use issues.

I guess that I found trying to find care is just, especially with inpatient, is that there’s no beds available anywhere.

... each time I’ve tried to check myself into a rehab or mental health over the last two years, there hasn’t been much available. My brother actually had to go out-of-state to seek treatment.
... don’t think Massachusetts understands that because we’ve had friends with children that had issues and ... they’ve actually had to live in Maine to get help. It just seems, there’s not enough beds for children or anybody that has an addiction. ... and it’s really, really sad and people are dying left and right because of it.

III. Dissatisfaction with Care: Outpatient and Partial Hospitalization

Poor quality of care and lack of continuity
Consumers cited concerns about the quality of care due to poor care coordination, being a part of inefficient and ineffective care systems and receiving poor quality care.

She ended up in the ER, so in the hospital. And the care she received in the hospital had nothing to do with the care she had from the other doctor she knew. And they give her more medication in the hospital that adds to the medication she already had from the other doctor she was seeing. She had boxes of medications, she was able to get all of those medications from doctors in hospitals, ... She had met doctors and all of them gave her medication. But they were not connected. They didn’t know of each other, I believe.

You really have to search, you know? Rummage through so many doctors to find one ... ... and plus, they can’t even spend time with you especially when you go to a... private practice. They can’t spend time with you because they’re only allotted so much time with patients and you’re in and out so...

There are not that many good choices for competent therapists.

... nowadays when you go into a treatment facility, they keep you 72 hours whereas you used to go back in the day it would be a 28-day program or a 14-day program. Now they just want to detox you and send you out on your way without any help.

Several consumers felt they had received the bare minimum of treatment before being discharged from treatment, which resulted in a “revolving door,” with consumers repeatedly seeking care for the same issue.

That’s because there’s already people behind you. It’s just a revolving door. They have money to keep you for 2 or 3 days and then they let you go and then someone else comes in and they get twice as much money for another 2 or 3 days ‘cause you got the initial, the consultation, you got this one, you got that one and after that they’re just paying for room and board and a few things here and there which is still expensive but they more money with a revolving door.

...Yeah, you go back in again and it costs more money...Instead of doing it right, you know. And you still have to pay. I mean, when I hire somebody to do a job in my house, you know, if it’s done right, they don’t get paid until it’s done right. So the same should apply for medical care.
Sometimes ongoing dissatisfaction with care results in consumers not seeking care at all.

The reasons for me not seeking care is the quality, you know, the quality of care that I received. It’s never consistent. ... I feel like I’m not being heard. I’m dismissed, you know, that type of thing. And, you know, just pushed up, you know, pushed away … it’s very frustrating so ...sometimes I just give up.

Unavailable Care: The Impact of Waitlists
Consumers described the overwhelming impact on having to wait months to see a provider or get other types of outpatient care.

... I can’t imagine someone who’s calling and finally took this step to reach out for care and is told, well, you have to wait three months.

To get an appointment, it’s usually 3-6 months ...

...even if I wanted to start up [again seeing a psychiatrist] there’s so much ... there are waiting lists for everywhere.

... my primary care physician provides my medication for my depression and my anxiety because I just asked at [place] and he told the waitlist to see a psychiatrist would be more than six months.

... so many people that need help, they just don’t have the physicians to see everybody and when you do want to see a psychiatrist, you’re on a waiting list even at [place] could be 4-5 months because they just don’t have enough psychiatrists or psychologists...to see you.

So anyway, I happen to know that... tons of people want to go to [name] ... adults get turned away... and that's one of the biggest psychiatric departments in probably the country.

... I needed to go to outpatient... day services for mental health ... the waiting list to get in was just overbearing and it could’ve been a couple of months and... when you’re having a situation and you need help ...

IV. Dissatisfaction with Care: Need for Better Integration of Care

Several consumers discussed the importance of integrated care. Some felt that behavioral health and medical care providers should communicate more effectively, seeing a direct negative impact on their care when it did not happen.

I think better relationships between primary physicians and mental health is important and having it be in the same office.... I also think there should be preventive mental health medicine and noticing the importance of healthy habits such as free or reduced gym membership, yoga, mindfulness, meditation, nutrition, journaling, community outings, finding a healthy hobby, support groups and school awareness and support to prevent adolescent onsets.
For me, there’s a very physical medical component to my mental health because it is an eating disorder and ... I have more lasting medical issues ...

Just having communication especially if, you know, I see my therapist twice a week, they’re going to know more than my primary care who I see once a month ... so if there is communication [from my therapist then the] doctor might ask for another appointment or know what labs to run or what tests to do to see what’s happening based on my behaviors.

...having the mental health part of [health care] separate. I mean it’s changing in our society, but having everything separate with mental health just adds to the stigmatization of it and the embarrassment...

Two noted inherent frustrations in sharing mental health care information with their primary care providers.

I just try not to go, you know, into depth about something [with my PCP]. Like if I go in about ... whatever physical symptoms, I try to split that and keep them separate. When it’s all brought together, there’s just too much miscommunication and frustration.

When I didn’t reveal my mental health problem [with the PCP] that was actually pretty dangerous because the autism can affect my ability to communicate and symptoms and stuff like that so I do make sure that my doctor knows about it ...[I have] problems related to the autism like OCD so it’s helpful sometimes for a doctor to know, “Oh, so we’re not going to do this because all you would do is obsess about it.” So, that’s helpful but there are other times when I am expressing normal concerns and then being told, like, oh, you know, ‘I hope you won’t get anxious about this’.

Need for insurance policies to better integrate care

Some consumers noted challenges when health plan designs contribute to fragmented behavioral health and physical health care.

Behavioral health or mental health is often treated like a separate thing... on the back of my ... card... there’s like a different phone number for behavioral health and different people to talk to. And it’s treated like a completely different thing and often unclear ... So, it’s almost like the behavioral health benefits aren’t integrated in the overall plan which makes everything way more confusing. I like it all to be sort of unified.

Insurance should...look at the whole person, whether you have diabetes or heart conditions or mental health problems. I think it should all be on the same page. We shouldn’t be getting separate letters when you’re seeing a counselor and separate letters from your doctor and separate letters from the insurance company. It’s just overwhelming. ...for my son, that’s why he dropped out of all of that. It’s too much for him to keep track of ... he doesn’t go to the doctor and doesn’t get his medicines. You know, when he gets something like this, he feels inadequate and he feels like he’s letting himself down because he can’t manage it.
I don’t know if the insurance company ... could look at mental health the same way they look at physical disablement. It would go toward a long way toward equalizing the field.
CONSUMER THEME 2: CHALLENGES USING HEALTH INSURANCE FOR BEHAVIORAL HEALTH CARE

Consumers discussed many health insurance challenges around their care for mental health and substance use disorders. First, many felt that insurance companies had too much influence on their care, often dictating the care they receive rather than their physicians, therapists or counselors. Second, communicating with their insurance company often presented challenges, including understanding printed materials about benefits, understanding what benefits were covered after care was provided, getting accurate information about participating providers and being overwhelmed with the need to be an effective advocate. Finally, consumers discussed the barriers they found in choosing a health insurance plan that could meet their behavioral health needs.

V. Challenges with Coverage: The influence of insurance companies on behavioral health care

Limits on services
Many consumers perceived that insurance dictates the types of services and medications they receive, regardless of physician recommendation or direction. This influence is compounded by the administrative burdens to gain insurance coverage approval for care.

…it’s not what you want; it’s what your health insurance lets you do. So, we’re ruled and governed by the health insurances and if you want to go to the [provider] that you like, then that might not be covered by your health insurance so you have to stick to whatever they pay for ….

…we are depending on health care and if the health insurance…doesn’t cover all of those things, then you have the option to pay full, that’s your option. …the health insurance… govern[s] the places you can go and the help you can get. It’s not even the doctor. The doctor wants to send you to the best place but if your health insurance is not going to cover for it, how are you going to pay for it?

And there are caps on how many times you can go, right? So, let’s say that you finished all your sessions but you feel that you need more help. Then you won’t be covered … So, if you’re lucky enough to have the best insurance out there and you are able to pay, you’re good to go. If you have MassHealth, Medicare, you’re good to go. But if you’re … working [in order] to pay your health insurance …you get stuck.

… the way that it’s structured, the number of visits that you’re allowed to make within a certain amount of time that insurance is willing to cover isn’t enough for the care that you need…Basically, insurance might cover ‘x’ number of visits and that might not be enough.

So, my real problem was always the visits versus the care that was really required and one always outnumbered the number in what they were willing to pay for.
... providers would recommend a certain level of care and that would require a certain number of visits and sometimes, especially towards the end of the year before benefit cycles reestablish that that might not always line up and then you have to pay out of pocket.

**Limits on inpatient or partial hospitalizations**
Several noted the impact of limits of hospital stays or day treatment programs as a problem.

I’ve had issues where my insurance didn’t want me to be in the hospital any longer even though the doctors in the hospital were saying that I really needed to be there to continue treatment and ... they won’t cover residential care, they won’t cover day programs, ... things like that.

...after being hospitalized for several weeks ... there is a limited number of days in your lifetime through Medicare that you can be hospitalized. At thirty-two years old, I’m coming up against that number and I’ve got a long way to live and so that’s incredibly frustrating.

...I needed to go to ...day services for mental health and... they fought it through the mail... trying to prove if I really needed it.

**Limits on medication coverage**
Consumers were frustrated about limited medication coverage, poor continuity of medication, high out-of-pocket costs and undue administrative burdens—all having a deleterious impact on care.

Like I remember when I started with my journey with this depression problem and tried to commit suicide, the copays were like $5 and then they’ve gone up... the insurance ... decides what meds it’s going to pay for and what meds it’s not and if you’re on something that they decide they’re not going to pay for, they’ll let you have the medication because the doctor says, you know, this name brand only.

... you have the medicine and all the medicines are on a Tier. Tier 1, Tier 2, Tier 3. So, they’re picking and choosing now what they’re going to pay for. ... they may decide the medicine you’re taking now it may be a Tier 3 and all of a sudden, it’s a Tier 1 and it’s going to be three times more. I never see anything like it in my life.

My doctor wanted to put me on something new ... and the insurance company wouldn’t do it unless I tried something else first... And, you know, that wasn’t what my doctor thought was best for me and surprise, it made my anxiety a lot worse just like he thought it was going to. So I had to wait to do that, pay that copay, get that, take that for three days, feel worse and then get the new one and the new one is Tier 3 so it’s like $60.

Uh yea, one of the current medications I’m on... initially it was covered fine, and then a year passed and they required prior authorization for it and denied it after my doctor filled out the initial prior authorization and then [the company] sent her a more detailed prior authorization form ...so it turned out, my neurologist wound up having to fill it out instead of her, to get it covered, and so in the end it was covered but it was very difficult to get covered, and I
went I think 6 weeks without medication because I couldn’t get it covered, and it was $60 a day for the medication out of pocket.

One person discussed the need to expertly navigate the system to get care because of insurance limitations.

I do not have an option to receive care for eating disorders except for inpatient hospitalization which requires you to be medically unstable. [So] I see my therapists, outpatient and anything in between… I mean, I was speaking to two different residential programs at the same time and even my lawyers couldn’t get Medicare to either cover it or make it so my Blue Cross can cover it … they are treating eating disorders differently than other mental health. I can go to a depression partial but I cannot go to an eating disorder partial ….

VI. Challenges in Communication with Insurance Companies

Insurance companies share information with their members through plan documents, such as a Summary of Benefits and Coverage upon enrollment and an Explanation of Benefits after service has been provided. Almost all consumers shared particular frustrations with these documents and subsequent attempts to contact customer service.

Understanding benefits in general

While almost all consumers had health insurance, most were overwhelmed with their plans’ documents and struggled to understand their benefits.

... I’m not a cognitive learner, so to get all these documents, and have to try to sit there and read it and kind of absorb it... for years I have not even taken this information out the packet each fall when it arrives, I literally just stick it in a box, and I know it’s there if I need it for reference, I just automatically each fall do the same thing and hope for the best turn here... I know it’s not being very proactive, but I struggle reading these kinds of documents ...

A few provided suggestions as to what would make this information more easily accessible so that they could better anticipate what would be covered.

Just like, really straight forward, keep it simple, what’s provided, what’s not provided... areas of expertise, availability, scheduling...but less is more kind of thing? It gets, it’s too much to try to figure out. ... provide me the basics, and then a number that I can call if I need additional information. At least, that way I’m gonna read something, or take the time to view a video, versus not doing anything at all.

...people have different learning styles so maybe if there were like, say for example, short videos ... So that there’s different ways for people to engage and get the information.

...they just overly complicate the whole thing... it’d be really great if they would... very simply say “here’s what you can expect... here’s what things we pay for entirely, here’s what things you’re going to pay extra co-pay for and
what rate” ... so you’re not always guessing, waiting for that explanation of benefits to really know what happened.

**Understanding the “Summary of Benefits and Coverage”**

When shown the Summary of Benefits and Coverage, most consumers were not familiar with this document – which is required by law to be a concise document detailing, in plain language, simple and consistent information about health plan benefits and coverage. Of those who were familiar, they found it confusing.

... they’re generally confusing to me and it’s like I would... I usually have to call the insurance company to figure out what it is ... because it’s kind of abstruse and convoluted.

I find it very confusing in terms of how to read it. I mean, I do read... I can read it fine but I don’t know what it means to me...

... deductibles, out of pocket limit and it goes on and on and then when you get the premium sheet and you look at it together, it doesn’t match up and that’s why I find it confusing.

... I think it’s that the actual coverage is difficult to understand. There’s so many permutations and, you know, how many people in your family, and what the deductible is for a specialist, what the deductible is for a copay. Does it accumulate towards an overall deductible? ... I just think the content for it is inherently confusing.

One person learned information about insurance through peers rather than from insurance company documents.

... the people I know from groups I go to have pretty much, pretty much have the same coverage I do, so I usually find out things through them.... Cause I don’t read through this paperwork usually.

One person noted a marked contrast between how benefits for medical care and behavioral health are described.

I definitely find that the sections on what’s covered for behavioral and mental health is even more complicated than the physical health In terms of interpreting what’s included and what isn’t.

A few noted the need to call customer service to help them understand the information in the document.

... they’re not very understandable and...some of the ways that the deductibles work and the combination of that with in-network and out of network can get so convoluted that you can go back and look at it but usually you have to call someone and then they point to me to the line in the summary of benefits that explains what they did, and then I go oh, that’s what that means?

So, I will usually refer to the document as a reference guide instead of reading through the whole thing? Kind of when I’m getting a base idea of what I’d be looking for and then I’ll usually try to call the insurance company to make sure that I have the right information
Understanding how treatments/services are covered: EOB Forms
Most found the Explanation of Benefits (EOB form) --the statement sent by a health insurance company to members explaining what medical treatments and/or services were paid for on their behalf-- difficult to decipher.

I didn’t try too hard to understand it to be quite honest with you. They had stuff like original charges and write off and insurance payments and patient payments. How they calculated these amounts, I don’t know what I looked at… what I’m interested [in is if it] …matches up with the copayment that is listed on my benefits…. I mean, I didn’t try too hard. I always cared about the bottom line.

…receiving explanation of benefits, for me is a little frustrating …here comes this surprise amount that I have to pay that I did not know about… sometimes it does make me upset when I see my patient responsibility be so high, or the fact that sometimes I have a patient responsibility at all…

A few mentioned the need to contact customer service to explain EOBs.

... when you call to ask for an explanation that is on the EOB, the customer service representative is unable to explain.

..., they’ve made them simpler and simpler over the years to the point that there’s no information on them and they’re almost always… you just have to call and ask because the date of service is not helpful or, you know, it doesn’t actually say what the service was. It just gives you a code so I, I find them particularly unhelpful unless it says $0 balance. Like I’m going to have questions.

The need to invest time and energy in communicating with insurance companies
Many mentioned the having to “jump through hoops” to get necessary care, coverage or reimbursement, which can be made even more challenging for consumers with behavioral health needs.

Once they made me try [the medication] and once my doctor wrote the letter, then they were fine with it. But I didn’t have to fight it really hard. I just had to jump through all of their hoops, make a lot of phone calls and wait for the paperwork to go through and make sure the faxes happened and all of that stuff.

When somebody’s depressed, you have to jump through all these hoops. It takes a lot of energy and a lot of people are not going to do and that’s what the insurance companies are probably bartering on. That people will not jump through the hoops to do it or they can’t jump through the hoops to do it ‘cause they don’t know which hoops to jump through or they don’t have the resources so… um, yeah, I think that’s a big problem.

So, I think there are just… and then even when you are treated, for example for ADHD… mostly treated with stimulant medication which is the schedule two, II, etc. narcotic which is… you have to jump through a lot of hoops to get which is hard if you’re disorganized and very ADD.
I just went to the pharmacy and found out that it wasn’t covered and then I had to call the insurance company and be on the phone with them for like past an hour, then I had to email my doctor to get an override authorization and meanwhile, in the middle of the depressive episode, you know it’s a lot of hoops to jump through.

A consumer who is dually-eligible for Medicaid and Medicare and has additional private insurance discussed the challenges she encountered with claim submission.

... I have three insurances. It’s a nightmare. It’s a constant whether it’s appointments, hospitalization, prescriptions. You know, whether the provider’s submitting the claims, whether I’m submitting the claims for reimbursement. It’s a constant battle for me. If I had any money, I would hire somebody to deal with insurance for me because it’s so awful and it takes so much of my time and all of my brain power these days to be able to handle it.

Getting accurate information about participating providers
Several consumers complained about inaccurate provider panels in the directories on insurance websites. In these “ghost panels,” providers are inaccurately listed as either belonging to an insurance company’s network or as currently accepting new patients.

... the insurance company will say they have a provider, but when you call, they’re not accepting new patients.

... And if you call your insurance company they’ll tell you to go to the website and there will be a list of 400 doctors. Like, how is that helpful? But, you know, if you do an online search, there might be 400 doctors but none of them take your insurance.

I think that for me, it was difficult to kind of have a list of people that I could go to see but then have no idea whether or not they’re accepting patients. [It would be helpful to know] if they had like just an average wait time for seeking of patient services.

... there was actually a lot of confusion about whether a particular provider was covered or not. Because, as it turns out, my insurance had a carve-out by another insurance provider so that [provider] showed up as being in network in one way and out of network ... in another way...discovering after the fact when we submitted the claim that they weren’t even going to pay them as out-of-network.

Using the appeals process
While some consumers utilized the appeals process to challenge a coverage decision, many perceived the process to be time consuming and unlikely to be successful.

I don’t think any of them [appeals] have ever been granted.

... I understand that ... [the appeals process is] tedious. I knew that going into it; so constant contact back and forth, missing documents, and they call this provider and so forth. Long, definitely not easy.

We almost went through an appeal process and then just really evaluated what was involved in it and it was too much trouble and too much time so we did not do it but... um, usually you just pay the money.
The burden of the appeals process is compounded by ongoing mental health challenges, making people even less likely to start the process.

You know, when you’re not feeling good, it’s very difficult to be your advocate at the same time. It’s very stressful. I mean, that’s why you’re going because you have stress, anxiety and depression. And when you have to fight so hard for something, and… you just give up. So that’s pretty much what happened. You just don’t have the battle in you anymore.

VII. Challenges Choosing Health Insurance Plans
Some consumers are able to choose their insurance plan, through shopping through the Massachusetts Health Connector or through employer-sponsored options. Many consumers used “short cuts” to determine if a potential plan would fit their needs, considering price, limitations on referrals, out-of-network coverage, and whether current doctors are covered. However, most felt unprepared to choose plans based on their behavioral health needs.

[What I’d want to know is]…just the different coverage and the deductible and stuff like that come into play… I guess specifically what my current doctors already accept. And other chiropractic or random other services that they cover.

… I’d want to know how many visits were covered, I’d want to know which providers they covered, those would be the important things. And I’d also want to know what medications were covered.

… [I’m looking to see] whether I would just be able to set appointments on my own or whether I would need prior approval from my primary care doctor or from the insurance company.

… [I look for] first how difficult it is to get the referral and is there a specific place that you can only get a referral? … that is very important ‘cause it all depends on your referral how much money you’re going to end up paying.

… the number of visits. And then for the referrals ‘cause usually I don’t have a choice, it’s sometimes harder to tell if it’s HMO or PPO with my work. So, they’ll give you like a bunch of information but it’s not anything really helpful. It’s just, like, general forms online like fitness rooms or somethings like that. And I think it would be more helpful to have like a breakdown of the plan instead.

… I was obviously looking price per month. I was looking… to make sure that I could… send in the claims myself and get reimbursed is the big thing. Since I knew my providers didn’t take insurance from anybody.

A few were confused about how to anticipate behavioral health needs.

For many years, my son was actually covered under my healthcare plan… [he is a] qualified disabled adult dependent, and every year I pretty much chose which plan I would go on based on my expected [costs], you know as best as I could use a crystal ball to figure out what his needs were gonna be. That was probably the primary way I chose which plan we were going to go on. ...
You can read the [materials], but that doesn’t mean you can understand them...every time you have to pick your health insurance, I read them as carefully as possible and I find that I’m still surprised at some of the things that aren’t covered.

The copays vary and they keep going up. ... they charge you whatever they want and I’ve had prescriptions vary from $56 to $84 to, you know, so that’s kind of... it’s been unsettling. I don’t know when I go to the pharmacy what I’m going to pay for my monthly psych meds...

One person talked about access to a tool she had which helped her make decisions about selecting a health insurance plan based on her behavioral health needs.

[There was] this kind of cool calculator that you put in how many visits you thought you were going to have, what kind of prescription refills you were going to have... And they would tell you which deductible plan to go on to have the smallest out of pocket. ...I would sort of punch in expected hospital visits, doctor visits, that kind of stuff, and they would come back with comparisons of the plans to help me understand what my out of pocket costs were compared to my insurance premium contributions. That’s why it’s not a no-brainer to take the lowest deductible, because you pay more in premiums.
CONSUMER THEME 3: CHALLENGES IN MANAGING COSTS

Many consumers shared their struggles paying for care and medication, even though almost all had insurance. Common themes included a) excessive out-of-pocket costs; b) frustration and confusion around costs and learning about coverage problems at challenging times; c) the surprise at lack of cost transparency; and d) the decisions to get care outside of insurance networks.

VIII. The Burden of Out-of-Pocket Costs
Many consumers were frustrated and confused by the payment requirements of their insurance policies.

You just pay, paying, paying out of pocket. Most people don’t even meet their deductible and, um, and then there’s coinsurance, copay. It just never ends. And not only that, you’ve got your premium on top of it. We’re going broke, you know? It’s ridiculous!

... that whole interaction between out of pocket, in network, out of network, what’s going against your deductible ... I’m always surprised when I have to pay money and it doesn’t actually increase the amount I’ve contributed to my deductible. Like, what happened there? What is that?

So I had to wait to do [get a medication I didn’t need], pay that copay, get that, take that for three days, feel worse and then get the new one and the new one is Tier 3 so it’s like $60. ...the (copay) is challenging ...

... it’s unbelievable how they get away with this. It is truly amazing how they do get away with this. They overcharge for everything and I think that’s why people can’t seem to get healthcare ....

Um, you know, it’s getting ridiculous because every year the deductible goes up and the benefits go down.

These out-of-pocket costs often drive decisions around the kind of care consumers seek or receive.

... just like going to a new doctor and knowing that you would be wanting to see this therapist on a weekly basis, especially to get introduced to them and feel comfortable and it’s the idea of having to pay that once or twice a week that ... can be unreasonable...[its] either the co-pay, or having to meet a deductible first, as well as therapists who don’t take insurance.

... I live on a very fixed income, like a lot of people, so the cost of getting to the therapist on a regular basis might seem minimal to somebody but to me adds up at the end of the month.

...every time we’ve picked a residential program for my son, cost was probably one of the biggest single factors, because it’s so long term, and insurance doesn’t pay for it at all.
... (I didn’t continue with) the private providers that I could not use insurance through ... Because it would’ve been too expensive... And I couldn’t afford that. So, that’s pretty much what... forced me, into looking for county services which were a lot more cost effective. I think that turned out to be about $20 a week and they let me pay over time....

These costs sometimes prevent or deter consumers from seeking or receiving needed care altogether.

... places where I had booked an appointment and then they were maybe a few days before were looking again at my information and would contact me and say that ... I had a deductible to reach and that I wouldn’t be able to meet that, and I’d be paying the full price for probably the remainder of the year. ... both times that happened I cancelled the appointment.

[I’ve had] a fear that I won’t be ready to leave [the facility when the insurance company mandates] and I’m gonna wind up having to pay out of pocket for expensive treatment.

IX. Surprise at Costs of Care Disclosed After Service Provision: The Need for Price Transparency

While most of health care lacks price transparency, the surprise of costs--disclosed long after service provision--is particularly problematic for those with mental health or substance use concerns. Consumers spoke about anxiety, worry, or hesitancy to seek care due to the lack of price transparency.

...and then ... two months later, you’re getting a bill in the mail for an amount that you didn’t even, like they couldn’t even approximate how much, you know, whatever your services were going to cost. So, it just makes you a little bit hesitant to go to a doctor because of that.

... well, you find out [how much things cost] when you get the bill and then you realized that this wasn’t covered and then you come through the battle of appealing and working with the insurance company to try to either get them covered or pay the bill.

It would be helpful to know [costs, or what’s covered] up front, especially with mental health, because you’re already in a situation, you know that’s why you’re seeking help. To know what to expect, just to lessen some of that anxiety.

You know... if I go to a department store, there’s price tags on the clothes that I want to buy and if I go to a restaurant there’s price tags on the food that I want to buy... but for some reason when I go to the doctor, it’s just ...yeah, we’re not going to tell you because you’re so desperate for help you’ll pay anything. And it just kind of gets that feeling. And that preying upon the desperation of people who are really looking for help, by giving them this EOB with this exorbitant amount on it, a month and a half or two months later is just like whoa.
Some mentioned specific concerns about out-of-pocket costs and how they fit in with overall costs.

[I wish I knew] here’s what things you’re going to pay extra co-pay for and what rate. … so you’re not always guessing, waiting for that Explanation of Benefits to really know what happened.

Yeah. If I know I paid the copay, you know, and I get it like three months later, like… okay, then what do we do? We spend 45 minutes on the phone.

… I’m always surprised when I have to pay money and it doesn’t actually increase the amount I’ve contributed to my deductible. Like, what happened there? What is that? … I want it all to be a lot less complicated, so it’s not so surprising

So by the time… your deductible is met if you’re lucky, you still owe 20% and you still have to pay a copay for the visit and then you have the medicine and all the medicines are on a Tier. … So they’re picking and choosing now what they’re going to pay for. …they may decide the medicine you’re taking now it may be a Tier 3 and all of a sudden, it’s a Tier 1 and it’s going to be three times more…

X. Deciding to Pay for Care Outside of Insurance Plan

A few consumers discussed their decisions to pay for care out-of-network in order to receive quality care they felt they needed.

[One big problem is] having to change insurance [or] change care providers because of the insurance is like, backwards. So, people aren’t going to do that because … “my mental health is more important than the insurance company’s concerns about [cost]” … So, we [consumers] pay the money.

I’ve definitely had problems locating … specific clinicians who I trust so I actually do travel quite a bit and pay some out-of-pocket to get reimbursed from insurance.

Pretty much everything [is self-pay] except in-hospital care and the once a month psychiatric visit. So, any residential support, any kinds of group therapy situation, group home, any of that has all been self-pay.

Many noted that their providers no longer take insurance, or never took it in the first place.

Well, I was able to [use my insurance benefit], at first, and then my psychiatrist decided that … [the insurance company] was being too demanding of him to show them his office notes, which was his opinion and I agreed that those are supposedly confidential. So, he left the practice and now I have to pay cash…

Like my therapist who I saw over many years … took insurance and then stopped taking insurance and, I mean, she was very generous to me. I was
young at the time and I didn’t make a lot of money and let me use a sliding scale, but her full rate at the time I stopped seeing her was like $265 an hour. And you know, that’s a very small percentage of the population who can afford that.

But when [my mental health provider] went into private practice, he didn’t take my insurance so [I’m] paying out of pocket for it.

…when I went to private therapists and I would speak to them beforehand …and …, that’s when it would just kind of come out as in, ok we don’t cover this, or your insurance doesn’t cover this, so forth, so you can either self-pay or we can try to submit it to insurance and see if they’ll take it?
XI. Perception of Fairness and Equity in Behavioral Health Care vs Physical Health Care

Overwhelmingly, consumers perceived a profound inequity of how behavioral health problems are treated as compared to physical health care. Whether these experiences indicate potential violations of state and federal parity laws, their experiences suggest it is still more difficult to access mental health or substance use treatment than other types of health care.

Health Insurance Benefits
Health insurance policies related to behavioral health were perceived by many to be unfair and inequitable when compared to those offered for medical care. A few pointed to inconsistencies in how their health insurance managed their behavioral care differently than their physical health care.

You go to PT and they give you whatever it is, 6 or 8 [visits], and then you can get another 6 or 8, and you're never told [by the insurance company], "oh you don't need anymore." You know, if the clinician says you need more, you need more. And that's just not the way it is on mental health. Some of the plans just cap you, but a lot of the time they just push back and say no, you can only have one visit a month... I use PT as the example because it's similar in a sense, in that it's something that's sort of ongoing and regular...

...And then the other thing that's really different is that there is chunks of things in physical health care that are paid for free, like preventative care, like there's nothing, nothing that's free. There's nothing encouraging you to take care of yourself, proactively, on the mental health care side.

And you hear it routinely that you're capped at a number of visits, but...even before you reach the cap, [companies] push back and require additional paperwork from therapists to justify that you need continued treatment, in ways that you know, your PT can just say "yeah...they need more."

My psychopharmacologist is billed as a specialist so it's $35 copay but my son's therapist is billed as behavioral health ... there's a copay, but then there's a limit on visits.

Several discussed differences in coverage and price disclosures between behavioral health care and medical care.

I definitely find that the [information] on what's covered for behavioral and mental health is even more complicated than the physical health in terms of interpreting what's included and what isn't.

So I recently went to this medical doctor appointment...and they told me up front, they said these are the services you're looking to get in today's appointment and this is going to be the approximate cost we're going to
charge the insurance company, and this is the approximate, based on your coverage that you have, [cost that] ...you’re responsible [for]. And ...it made me feel like I was a little bit more in control of the situation versus [in mental health] I just need care and I’ll pay for it how ever I’m going to pay for it later.

It just doesn’t seem like they pay as well for mental health coverage...Just the deductible. It seems like they’re covering a smaller percentage of what it costs.

... I saw my doctor for sick visits, the deductible would never be that much [as it is for behavioral health].

Different expectations around care delivery

Inequities are often pronounced during the delivery of care. To, me it’s like night and day, my... mental health services versus primary medical care, they’re complete opposite. I can call my primary provider and hear back from their office within a day. It doesn’t take me three months to get an appointment. You know, the information is readily available, it’s more user friendly... I’ve called mental health providers that have never even called me back to let me know whether or not they’re taking new patients. It’s a complete contrast. Many noted the inherent differences in finding a qualified behavioral health provider as compared to a medical care provider.

I’ve found that it’s much easier to find providers who take my insurance for physical stuff, that generally it’ll be the first place I call and they’ll take my insurance, versus calling around [for behavioral health]

... I feel like the medical or physical aspect of it is a lot easier, is a lot more streamlined, ...just trying to get in the selection of doctors, you know, the ease of trying to find care is a lot ... better than [it is] on the mental health side. ... they don’t call you back, or it’s just trying really hard to get in to seek mental health care versus physical care

It’s so much easier... you can just call your primary and they can fit you in. And that’s it.

Much easier for me to see my primary care doctor and get my flu shot, my vaccines, my mammograms, anything else I need done is much easier to do that...I can make a phone call and make an appointment and I’m in.

To get a [behavioral health] appointment, it’s usually 3-6 months and then ... even physical medicine doesn’t take that long.

.... when you go on your insurance website and you look at the physicians that are available for whatever you’re looking for, there’s usually a nice list, and you can call around and try to get someone who is taking new patients, with your insurance, and it’s usually not these loopholes or caveats where, yea we take your insurance but we just don’t take that type of insurance for that type of issue. It’s a little bit more simplified [with primary care], not as many loopholes.
I feel like it’s more difficult to figure out who’s covered for mental health services... [I go] online with my insurance company, where I’m first trying to filter through online to figure out who … they cover, and much more often the people they have listed for mental and behavioral health services are incorrect. They no longer cover them, or cover their services.

One consumer compared the need for emergency care, how it is differently treated for those with behavioral health concerns, the need for providers who can treat those with mental health or substance use issues, and the impact of “boarding.”

Triaging physical health problems like when you go to the emergency room [versus] when you should just come to the doctor and when you should come in 6 months and it’s the same thing for with mental health and it can be just as emergent as a physical problem if somebody’s ... possibly suicidal. I think it’s harder to get... it’s the access, there’s no real “mental emergency room” where you can connect with people who really know what they’re doing in terms of substance abuse.
CONSUMER THEME 5: THE NEGATIVE OF STIGMA ON BEHAVIORAL HEALTH CARE

XII. The Impact of Stigma on Care

Stigma - the often internalized negative beliefs, stereotypes or perceptions about persons with behavioral health needs -- creates a number of barriers in seeking care. This includes lack of disclosures to primary care providers, friends and colleagues, as well as avoidance in seeking care.

Anticipatory fear with providers

Stigma often creates anticipatory fear for consumers when seeking both behavioral health and physical health care.

(When I get care from a doctor) ...it makes me feel like I have to hide stuff, which is really a bad thing to do if you have an alcohol or drug problem. To lie and hide stuff. So, you know, it kind of feeds the stigma ...

(I have) fears of how I'll be treated during treatment, like from providers or staff members. Especially in hospitals I've had bad experiences where I've been treated very badly by staff.

I can't explain it but it's... I'm like even embarrassed to turn into this folk's office in case people will see me on the street going there.

Lack of disclosure to Primary Care Providers

Fear of stigma contributes to many not wishing to disclose behavioral health information to their primary care provider. While a few noted that it was important for primary care providers to know about mental health or behavioral health for which they were receiving treatment, they also felt this knowledge could be problematic.

...they talk about HIPAA but I've seen HIPAA not put into play... I don't like the idea of that when I do see a psychiatrist ...whatever notes are being written down, they're shared with everybody, ... I went to the eye doctor and he was reading my... the psychiatric notes from my psychiatrist and that really bothers me because I feel that I should be able to have a choice if I decide to share that. When I ask my primary care about it, he says that that's part of your health care and every one's in your care together but I don't believe that. ... if I decide to share it, then, I can give permission for that. But I find my shredding them 'cause I don't want everybody in my doctor network to really know how I feel. I feel like I can't share. It's just spread too thin.

If you're going in for like... you know, whatever physical symptoms with your primary care, they're going to ask you, like, “are you on any medication?” and then they want you to go into everything if like the records aren’t consolidated and it’s just a little frustrating. ...there is that stigma that goes with mental health treatment as well as, you know, alcohol or drug abuse too. ... I've had... friends that had to bring it up and it's awkward.

[Telling my primary care provider] would interfere with my other treatment. Like for example, I have ADHD and that’s something ... I talk about with my primary care provider but I didn’t want to like try to like conflate the two issues
kind of. And so, I just kind of avoided talking about depression with my primary care provider. I know there is a whole list of questions that goes along with that and I didn’t want the treatment for depression to affect my treatment for ADHD.

I can just say that, uh, this is something I have read about and have expressly tried to avoid for this reason [stigma]. This is the reason I never talked about it with my primary care physician. And I’ve tried to seek treatment on my own.

Lack of disclosure to peers
Stigma affects how consumers choose to disclose their behavioral health problems to coworkers and friends.

People have so much to offer. I don’t think [people] in our society (say), “well, he has a heart condition so he can’t do such and such”. But they do do that when you have a mental health issue. I really feel that it needs to be worked on a lot.

Even among people at work… just a few of my friends I actually told about my condition because there’s a huge stigma because in the news, people with bipolar go nuts and have terror rampages, you know, whereas for me it’s just like occasional depression and once in a while I feel great. But, you know, it’s nothing special. It’s like ordinary life. In fact, some people go, “oh I have that, I have that” and so they’re trying to relate, but for the most part people are just like, “Oh, bipolar, you’re going to be a terrorist!”

Other consequences resulting from stigma
Sometimes family members were the least likely to understand that help was needed for mental health problems.

My high school guidance counselor … got my parents involved who were very reluctant to seek care… my main difficulty there was just getting my parents to realize that there was an actual problem that needed addressing.

Programs designed to help people with behavioral health problems are not immune to stigma. Two consumers discussed their own experiences.

…it’s subtle sometimes but in places that I work … one of the programs that benefits people with addiction problems is kind of the odd step child and we’re not included in a lot of decisions and sometimes somebody needs our room, ‘well, you’re not a real program’. I’ve had people say that. ‘You’re actually a different, you’re not a real program.’

[In Boston] they’re starting these things called recovery centers and they’re community centers that are supposed based around paths to recovery from substance abuse and that’s a good start for people to come in and to, it’s consumer-driven rather than to put in to a place or told you have to go somewhere. But… there’s still this stigma wrapped around [recovery centers in Boston]. People will see, ‘okay, you know, I’ve worked on the street so I really have to be in this backroom with the group because I don’t, I can’t be seen and I’m really nervous about it,” and that’s just part of what we’re all saying about the stigma, I think.
PROVIDER THEME 1: CHALLENGES PROVIDING CARE IN AN OVERBURDENED SYSTEM

Some providers identified specific challenges regarding care in the inpatient setting, including waitlists and delays in care, emergency room boarding and emergency room care. A few providers mentioned their frustration in an overburdened system and the reliance on emergency rooms.

However, the focus of most group discussion was on the numerous challenges of providing care in the outpatient setting, including partial hospitalization. Many providers discussed the increasing prevalence of waitlists and their impact on patient care, especially at times of crisis, and how waitlists are even more prevalent for MassHealth members. Providers discussed the limited availability of outpatient services in general, and the challenges in making appropriate referrals to meet patient needs and ensure high quality care. Discussion also focused on the lack of availability, delays and discontinuity of care for particular populations, including for people needing medication assisted treatments (MATs), people who are not citizens and/or speak Spanish, and people from ethnic or racial minority groups. Several providers expressed concern about the ongoing shortage of respectful, culturally competent care.

Discussion also focused on the effects of an overburdened system on the quality of care, including delays in care and the burden of searching for care. These challenges undermine consumers’ motivation to seek care, as well as their trust in care once the receive it.

XIII. Challenges of Providing Care in the Inpatient Setting

Waitlists and delays in care

Many providers were frustrated about the limited availability of beds for their patients. “More beds and longer stays” was the overarching request from many of the participating providers.

I know that our clinicians in our psychiatric emergency service are often really frustrated trying to help people … find inpatient beds and …the beds are really inadequate.

… [there’s not enough] … inpatient psych beds. They’re just really hard to find, and so it feels very frustrating not only for you as the clinician or provider, but also for the patient to have them sitting there and say, “I can’t get you a bed, I can’t find a place for you to go,” even when they’re at that critical moment where they say they want help. And that’s just really, really hard.

The shortage of beds may be especially problematic for people with substance use problems who may have only recently come to recognize their need for immediate care.
... when I worked with substance abuse clients, when they get brave enough to be honest and say ‘I need help, I need to go’, you gotta get them at that moment and you can’t. There are no beds... the accessibility is awful. It’s just really really hard. And it makes our job really difficult...

...[there’s]...not enough detox beds, particularly for patients with public or no insurance ...

Emergency room use and boarding
A few providers mentioned their frustration in, and reliance on, emergency rooms for their patients and clients.

Sadly, the hardest thing is to have to send them to the local emergency room, and you know, they sit in the emergency room and wait for the appropriate bed to open up. And sadly, I’ve heard of people who have had to stay 20, 30 days, especially adolescents, waiting for the appropriate bed.

... we don’t have enough psychiatric beds and ... we have such a long waiting list in emergency rooms especially for children...

Well, I think that because of the lack of access to care, and the inability for these people to access services, we’re overburdening our community and major hospital emergency rooms, and our emergency rooms are now becoming a treatment facility, which is just compounding the problem.

And [insurance company] has now suspended the need to be evaluated in an emergency room before you get admitted but a lot of the other insurance companies still do that.

One provider spoke about how the lack of available beds is related to the financial viability of inpatient facilities.

... I think one of the reasons why we don’t have enough psychiatric beds and why we have such a long waiting list in emergency rooms, especially for children, has been how insurance companies have made it very difficult for inpatient facilities to survive financially. And so, I think that clearly has had an impact on patients ...

XIV. Challenges of Providing Care in the Outpatient Setting

Waitlists and delays in care
Many providers discussed the increasing prevalence of waitlists and their negative impact on patient care, especially for patients in acute crisis.

Well I’m gonna say, sometimes 4-6 weeks, maybe you can get an urgent appointment in two weeks? But that’s two weeks too long.
So, you have someone drowning, who would probably really benefit from ... treatment, and they can’t. The waiting game. And bad things happen during those waits sometimes.

... there have been cases where we got life or death emergency referrals where I, you know, sat down with a person and then eventually tried to make arrangements for them to see another outpatient provider, and it was a three-month waiting list for out-patient.

I work in a group practice... but there’s a lot of people we turn away because we can’t get them in or there’s some complication ... we try to provide services pretty quickly, but again lots of people get turned away.

...where I work. ...this is the first time we’ve had to have a waitlist in 65 years ....

A few discussed the impact of waitlists on children.

   Especially children. I think it’s... some of the waits are incredible.

   It's even worse for kids with autism spectrum problems or developmental disabilities.

Several providers discussed how waitlists are even more common for MassHealth members.

Yea I’d say that more than half of [my MassHealth patients] are awaiting calls from clinics to say they have a spot to see them.

I think for the experience at my clinic, a lot of the clients ... some have tried for months to find someone who will take MassHealth where there isn’t, you know, a wait for months and months. ... if they have MassHealth, they’re looking at between 6-12 weeks wait... we get a lot of court-mandated folks who need like an appointment like yesterday.

...it’s very difficult to find psychiatry for patients who need it who have MassHealth.

I think for the experience at my clinic, a lot of the clients ... have often said they have tried calling so many different clinics and people in private practice ... some have tried for months to find someone who will take MassHealth where there isn’t, you know, a wait for months and months. I think there seems to be such a huge shortage of places that will accept MassHealth for therapy.

It’s very difficult because we do see people with such complex trauma and undiagnosed everything, which is probably why a lot of people self-medicate, and so you want to get people a psych eval, and if you have MassHealth, it’s just not going to happen right away, at all ... you have to get them an appointment to get an intake. Which can take a while. Then they do the intake, then they’re assigned to a therapist who has to see them three to four to five times before then they’re ... referred to the psychiatrist, which can take months. So you have someone drowning, who would probably really benefit from that type of treatment, and they can’t, the waiting game. And bad things happen during those waits sometimes ... MassHealth is really bad about helping people.
Limited availability in the face of increasing demands
Providers discussed the limited availability of outpatient services in an overburdened system, and the challenges inherent in making appropriate referrals.

...in terms of outpatient mental health, so many places are closing. You know, even in an era when we’re increasingly aware of an elevated need...lot’s more places are shutting down than are opening up.

Just the demand for... we’re behind the curve in providing Medication Assisted services in our clinic. We have a couple providers who prescribe a limited amount of Suboxone but they don’t have a coordinated program so... people seeking ... Suboxone or... Naltrexone... you know, we hear that they’re having trouble finding providers and as a result, they’ll end up buying these things on the street.

Some providers spoke about the challenges in making appropriate referrals to meet patient needs and ensure high quality care.

... most patients who have substance abuse have dual diagnoses, their underlying issues are mental health issues and sometimes you’re unable to get them both of those needs at the same time.

They’re able to access a service, like getting into therapy, but they need to see substance abuse [provider] or a psychiatric evaluation isn’t available. So even if you can access one thing, you can’t access other things.

... finding clinics that will take higher risk can be really difficult and they’re the ones most in need.

There are no psychiatrists that are accessible to [my patient]. None that he can go to. ...we’re just working without medication which may be able to do but it certainly makes it a lot harder and it’s really... been quite eye-opening for me ... [I am] trying to do what I can but the system is just not organized at all to support this work.

Besides limited availability, one provider was confused around how to make the best referral.

When there are some available, there’s kind of competing agencies, and it’s hard to know which ones provide the best service, or how do I choose, or things like that.

Limited availability, delays and discontinuity of care for particular populations, including for people who speak Spanish or who are not citizens

... we have a number of patients ... whose immigration status may not be a legal permanent resident here or a citizen, and so, often those folks have, you know, free care, they have Health Safety Net. And the lack of services there is just unbelievable, like they’re just so, they can receive outpatient visits and they can receive meds at certain hospitals, but otherwise the ability to get them services particularly at other substance use and/or mental health services is just really compromised. ... those are typically the clients, the
patients who have the highest level of need and are at the highest risk, and yet you can’t really get them connected to services and so we’re often doing piecemeal work, like getting them an appointment here or there but not really getting them fully connected.

… a lot of places are closing, like I can think of a particular program locally to us, that used to provide a partial hospitalization program specifically for Spanish speaking clients that closed …and since then there are no partial hospitalization programs in the state, with one exception I know of, for folks with mental illness. And so what do you do when someone who needs that level of care doesn’t … meet criteria to be inpatient but can’t really go back out into the community, can’t be sustained in outpatient care, and is Spanish speaking. There’s just nothing there.

…there’s a huge huge huge need for more Spanish speaking services. Both outpatient mental health services, partial programs, finding any kind of provider who can provide culturally competent Spanish services in Spanish is really really challenging, even in Boston.

For people from ethnic and/or racial minority groups
Several providers indicated concern about the lack of care that is respectful and culturally competent, especially for those from different cultures and/or with Limited English Proficiency.

It’s very hard for people to find providers that are culturally competent.

… you don’t earn enough to live off of… you end up [with providers from]… a particular demographic … And it means the people providing therapy aren’t necessarily going to come from the array that the patients are.

… cultural issues [are a major issue]. Who’s available to treat whom, what do they understand, do they understand their background?

And a number of my clients of color and immigrant clients, where you’re throwing in maybe a language issue …they’re just not getting the same level of care. And so … they just don’t put the effort in following up or following through because they’re going to assume everywhere else is the same… by the time people get to us, they really are quite jaded with the system so I think an overall disrespect, especially with people who have co-occurring disorders or substance is one of the issues, is a significant barrier.

XV. Consequences of Delays in Care

How the search for care burdens consumers
Several providers discussed how consumers – especially those already struggling with a mental health or substance use issue – are overwhelmed by both finding and accessing care.

… some of my people who have multiple problems and no access to media or they don’t have a smartphone or they don’t have any kind of… I mean they could go to the library to get some information but it’s very difficult to find reliable information to get hooked up with medical services even with
MassHealth. And so, I spent some fair amount of time supporting people in... in trying to make those connections. It’s been extraordinarily difficult.

They all have some form of diagnoses but the MassHealth patients seem to be the most multiple-problem... it’s more difficult for them. They don’t have as much access to resources and knowledge. Some of them are quite bright but this has been very difficult.

It’s such a confusing system for patients. I think that they often feel just kind of beaten down by it.

.... if we think about the people who are most likely seeking these services...if you are cognitively compromised... if you’re living with major depression and ... if you’re struggling to function, it’s really hard to retain this information or to even think about [self-advocacy] because your brain just isn’t in that place, you’re not able to think as clearly ...

One provider described how patients, often desperate for care, pay the full cost out-of-pocket in order to circumvent delays.

... there’s a [psychiatrist] pretty close to where I work and he’s very expensive, he takes cash if you don’t have the one or two insurances that he takes, and he will get people in within days. And I have people that are so desperate that they will try and come up with that money. And it’s just awful.

A few providers discussed overwhelming administrative obstacles for consumers to access care.

... I see people in a homeless shelter and even if I can get them set up in clinics or with programs, it’s very hard for them to literally get there. ... one of the hospitals requires that the morning of an appointment that people call to confirm it. And sometimes that’s just literally not possible, you know, they can’t do it. So, I think some of those administrative issues are pretty intimidating for a lot of patients.

Something that I’ve found ... my current clinic won’t take patients who have been hospitalized or pose significant risk. ... having worked on the side of trying to discharge patients from the hospital, finding clinics that will take higher risk can be really difficult and they’re the ones most in need.

I am a provider for MBHP [Massachusetts Behavioral Health Partnership] but those patients by and large have many problems and it’s not always appropriate for private practice.

... about transportation ...the PT1 transportation program cannot be signed by clinical social workers. I think it has to be a psychiatrist or a medical doctor. [So] I’ve had ... a lot of difficulties trying to get that program to work for my patients and it really has directly impacted someone coming in. You know, they don’t have the money, they take three buses or you know, it just is... they come much less frequently than they should or they would otherwise.

...often the people who are the most in need [of a bed] are behaviorally disturbed and many units will not accept them.
Motivation to seek care and trust in providers
The lack of availability or accessibility of care can also undermine trust in care and motivation to seek such care. A few providers mentioned the significance of missed opportunities when consumers are unable to get the help they need in a timely manner.

... First of all, there’s such a huge distrust of psychiatry. A lot of the people I see have had terrible experiences.... And to even get them so that they’re willing to see somebody is very hard. And then if they can’t actually get there or it takes so long, they become very discouraged with the whole process.

Now mental health and substance use is dangerous, when someone is ready to go and get help, you have a small window...

... most people who are calling ... by the time they get to us, we’re lucky that we get to hear from them at all because some of them give up after the first 3 or 4 calls and just assume that they’re not going to get help.

... you have someone willing to go but you have no place for them to go, and you lose them in that moment...
PROVIDER THEME 2: INSURANCE AFFECTS THE DELIVERY OF BEHAVIORAL HEALTH CARE

Providers spoke extensively about how working with insurance companies made their delivery of care, as well as the financial viability of their practices, difficult or even unsustainable. Areas of concern included: insurance interference in treatment plans and medications; uncompensated time burdens needed for appeals and authorizations; and the impact of low reimbursement rates, especially for their MassHealth patients. Many providers discussed an obligation to advocate on the part of their patients, sometimes with reluctance because their time was not compensated. In addition, several spoke about profit-making being the sole priority for insurance companies. All of these topics led to a singular conclusion for many: to stay “in business,” providers must reconsider participation in insurance panels.

XVI. Challenges Working with Insurance on Behavioral Health Care

Pre-authorizations and influence on treatment plans
Most providers felt that insurance companies had an undue influence on the kind of care they were able to provide to their patients.

... insurance really does often, dictate so much.

... it’s become almost a... the practice of most our patients, psychiatric clinics as well as community mental health centers, that their guiding principles of how they practice is more heavily weighted by what the insurance tells them they can or can’t do than by what’s really best for the patient.

... what I find heavily influencing their decisions can be boiled down to the cost of care ... [they have] so much power in influencing how healthcare and medicine is practiced with very little reliability involved and so their response often is ‘we don’t tell you what to do, we only agree to pay or not pay’. But I think their de facto ability for folks to pay or not pay for care is almost as if they can either get it or not get it. With some of the cost of the medications, if an insurance company decides not to pay for the medication that we’ve prescribed, they’re basically limiting access to that treatment.

What I’ve seen happen is well-meaning clinicians ... are pressured to have people discharged from the hospital ... and so they often get discharged too soon. Or [providers] get pressured to ...almost all the medications prescribed can take weeks to months to really know if they’re being truly effective. But often these clinical decisions are made in a very short period of time and I find sometimes the lack of time to see the clinical impact of those decisions can lead some practitioners to either overmedicate or medicate at a much higher
dose. I often find that I have to readjust the lower medications once they leave the hospitals because there’s a push to say that we’re doing something in order to justify [costs in] the hospital.

**Needing to “play the game” to get treatment plans approved**

A few providers described that they had to provide inaccurate information in order to get insurance companies to cover needed services.

I had a patient who just needed rehab. He’d been detoxed but he needed rehab and [name] doesn’t cover that; it will cover detox... it’s like playing a game. You have to play a game and do what you need to do to get your patient what they need. It’s a shame that it is that way.

Sometimes on my end as a nurse, I embellish, with the insurance plans, to try to get my patient what they need... Um, you know, with regards to trying to get them medications or trying to get them services that they need. Um, you know about using the word lie, I do what I-s sometimes I do what I have to do to get my patient what they need.

But I do find the prior authorization forms to be time-consuming and ...I sort of wonder what their purpose is ... I do them online and there’s boxes that I have to check. [There’s]... often not an applicable box and so there’s like something about... the client’s risk for self-harm ... and I have to choose mild, moderate or severe even if there’s none and so I don’t like having to fill out things that don’t actually accurately reflect the patient’s status in my care. But I go through the motions any way so I can get the authorization for sessions.

**Influence on prescribing behaviors**

Providers expressed frustration that insurance companies disregard their expertise in prescribing medications and the negative impact on their patients.

... if I use another medication that may not be as high risk ...there have been times where I’ve had to fight to get it approved and I’m thinking not just about the patient’s immediate well-being but ten, fifteen, twenty years from now. If I can reduce their long-term side effects of the medication of the child or the person, I would prefer to do that and so to me the cost of the higher medication is benefitted by the long-term well-being of the patient.

First of all, if you’re going to be thinking about what’s best for the patient... I know population data is very important, but every individual is different and you have to trust often the people closer to that individual to tell us what’s really going on. So theoretically I think I have a reservation about the idea about someone further away without the treatment or knowledge to make a decision about it....

And as a clinician, when you’re working with a patient and you know them and you know what they need and they’re ready to get it and it’s denied because it’s not cost efficient for [insurance], it’s dangerous.

And so, I’ve often found that after I speak with [the company] they agree with my clinical decision but if ... I’m really busy ... the patient [goes] for a period of time without the medication or without their recommended treatment ...
The demands of (pre)authorizations, denials and appeals
Several providers discussed the added time burdens needed for appeals and prior authorizations. In some cases, the extra work made them reconsider participation in insurance panels.

... I don't think that the inconvenience of the provider authorization forms, which I hate, impacts my patients because I take care of it and I've been lucky that, even when I've been denied, I've been able to get it approved eventually. But I think the impact is [that] people decide not to take this insurance. But like for myself doing fee-for-service work just isn’t sustainable.

When you appeal, it’s so intrusive the material they want and I think patients really feel quite violated by having to give out information to somebody they don’t know and who they don’t really know, you know, how they would be treated. So, I think that has been a problem for me and it was one of the reasons I stopped taking most insurance.

... I’ve spent half an hour, thirty-five minutes talking to one person after another trying to get a prior authorization for a needed medication.
And...there’s no reimbursement whatsoever for this. So, it feels... it feels like they’re actually just driving people right out of accepting insurance.

...we had to waste a lot of... I would say, I don’t know whether it was wasted time, talking through what I would say or not say and what I would reveal or not reveal. It was definitely an issue in treatment.

I specialize in personality disorders, so if I’ve been seeing a patient for the long term, which is ...clinically indicated. I often find that they deny my authorizations... at about a year or 18 months, and I can only induce them to... reissue the authorization if I furnish them with more and more clinical detail, which I in my opinion they don’t really have a right to know or ask for?
But [that’s just] a hoop essentially.

One provider said that these hassles drove decisions about how many patients with insurance vs. private pay he would see in his practice.

... so I took patients with me from the clinic into private practice and I’m pretty committed to that population but I won’t take any more patients [with insurance] ...I’d be very careful in terms of taking on someone who required all of these authorizations and forms and things that I don’t want to spend my time doing. So I think the patients themselves that I have... I don’t tell them about it but I wouldn’t take more. I’d like to.

A few providers mentioned how insurance denials, especially by MassHealth, affected patient quality of care.

... I have had MassHealth and various MassHealth products deny authorizations because the patient is getting better, and therefore they must not need therapy as much. ... I’ve had denials because they’ve stayed the same and why aren’t they changing, and I’ve had denials because people get worse, so “clearly what you’re doing isn’t working.” So, this is all to say, that no matter what, at a certain threshold you’re going to be denied and it’s totally lacking in reasoning.
... [plans and] MassHealth in particular...denies visits to a number of patients who they think aren’t doing well enough? So sort of insurance companies making decisions about a client’s level of functioning, if they’re not making enough progress in treatment or in therapy, then they cut visits down, and even when clinicians have appealed and really made the case ...typically ... the appeals are denied, even for patients who have really great mental health needs.

I do notice that there’s a really remarkable difference between MassHealth and the... various private insurance companies in terms of like the level of basically, invasiveness, parsimoniousness and like, just piling on of paperwork. Where MassHealth is much more onerous in terms of the requirements ....

I think one of the biggest challenges that I’ve had especially in the last year is just supporting folks who are on [private health insurance plan] or on MassHealth. And for some reason they’re getting bumped off their insurance which then hits their pharmacy. They’re not getting their medications and so... I’ll obviously send them to ... Health Care For All, but by the time they get it all sorted out, they’re months off their medications. I mean, especially, I’ve definitely noticed it with some of my guys on Suboxone where they’re ending up having to pay out-of-pocket which they can afford if they’re working, but a lot of them are not. And so there is a huge risk then for relapse. They’re not getting their MAT [Medication-Assisted Treatment] treatment...

... insurance companies in general, but really MassHealth in particular, uses this kind of fig leaf of evidence based practice... they’re highly selective in what they regard as evidence, and they often presume to know what the evidence based treatments are better than actual clinicians. And these are folks who are often not up on the current research ...anything that is supported by substantial scientific evidence that happens also to be extensive tends to be something that they’re going to decline to cover.

The role of provider as advocate
Several providers talked about their advocacy role around the appeals process, as well as the need to educate their patients and build confidence.

People often don’t know that there’s a process in place to argue with their response and their outcome and their explanation of benefits. You can keep going, pushing back and pushing back, and sometimes you get what you need, not perfectly, but ... They don’t know that they can. So, we try and work with people on that as much as we can. ...it’s that reassurance that we’re going to do what we have to do, we’re going to help you. And, but you gotta understand that you do have some rights to help yourself and we’re gonna help you do that. Because that has worked.

I think what I’ve seen is the majority of the time, if you fight hard enough, you can get certain things approved.

I’ve had some great successes with that, and I’ve had some horrible failures, mostly horrible failures, but people don’t know that that’s even an option.

One provider felt the limitations of his/her own advocacy role around appeals.
...because I’m working with folks who are usually dealing with co-occurring disorders and so there are some things in terms of dealing with the medical system at all. It’s generally not great. So they can’t access care for some reason. If they’re denied to another medical center for whatever reason, they don’t know they have an option. They just assume that there’s just a wall. And so, I find myself doing an awful lot of advocacy and dealing with Health Law Advocates and [Health Care For All]. Because they just don’t know that there’s an option that they can take. ...primarily the denial is mostly based on cost and not on what the client really needs. And, you know, I feel like a big part of my role in this journey in the last couple of years has been educating clients. But even with that, I don’t feel like I’m necessarily doing the most helpful job other than giving a phone number.

A different “bottom line” for providers and insurance companies

Several providers felt that the insurance companies only care about profit, rather than on quality of care. Moreover, companies’ “control” of care is based on the premise that providers (and consumers) will simply avoid the hassle of complaints or appeals, which ultimately increases profits.

...the first thing that comes to mind when we talk about insurance and reimbursement is that these insurance companies care about money. They really don’t help people get better, they don’t.

...[they] limit ... people’s ability to sort of get in treatment, which I think is sort of done intentionally... the managed care companies are contracted to manage these services all need to make money on the contracts that they have...these limits that they put on it are just simply make it insufficient for people to have enough access.

And so, I guess, I think of insurance companies often as gatekeepers...the insurance companies’ motivation is money right, you know it’s profit. And our motivation as providers, as clinicians is to help people heal, recover, you know, improve their lives in whatever way that is, and those are two very different motivations. ...it just-just seems like those two things are fundamentally at odds most of the time.

...so what I’ve come to realize is that it’s really not [the insurance company] saying that we want things to be practiced this way because we think it’s best. ...It’s saying we found that these... [services] trying to limit or deny has a cost associated with it. And so we’re going to [place] barriers towards getting access to whatever it is. And so it’s really, I think, a business based on attrition. If people give up and stop fighting, then [the insurance company] save[s] that money. And so I’ve often found that after I speak with them, they agree with my clinical decision ... So this is why I’ve come to suspect the motivation of the insurance company thinking ‘we’re trying to do what’s best for the patient’... You know, so I’m very dubious of that. ...But also, often when you do get to explain to them why it is, they’ll agree which would make you think, ‘well, then why did I have to work so hard to get it approved’ and the only reason I can come up with is because if you don’t, then it’s a service that won’t be delivered and it will be a savings for them.

... I have to say, I have a family that I’ve been working with that I had out-of-network arrangements... and [the insurance company] arbitrarily changed
their authorization and I haven’t been ... able to get [the insurance to] agree to pay... it’s been almost a year. ...And so, that behavior makes me suspicious that [the insurance company] priority is the well-being of our patients. I think often it boils down to trying to manage costs especially because they have no risk of an adverse event where [it’s] the clinicians who take the liability risks.

... for instance, for a young person who may have just been added another med by another provider and it puts them over the limit of the four... medications ... And if I’m away... and if the child needs a refill of any one of the medications, all four of them are not offered to them. And so, this doesn’t seem to be something guided primarily what’s best for the patients but I think often by cost.

XVII. “Why Should I Go Through All This Trouble If I Can Take Payment Out-of-Pocket?”

Almost all providers felt their acceptance of low reimbursements rates made private practice or fee-for-service care impractical, contributing to an unsustainable behavioral health care delivery system.

The reimbursements are all made to sort of make it more difficult and discourage, so there’s, there’s just things that make it very unfriendly and limit ... people’s ability to sort of get in treatment...

...for someone in private practice, the rates offered by [insurance] ... are so poor that it is disincentive to see patients. And I may do that in any case because I want to continue to see my patients... from the clinic but it is an unfair burden.

...the reimbursement ... makes outpatient psychiatry and mental health and substance use services just a terrible, terrible business... And I hate to use that term ... in our agency, our outpatient services lose a tremendous amount of money and we’re only able to keep them open because they’re supported by other parts of our company. ... the reimbursement is a humongous problem. ... it is difficult to recruit psychiatrists and nurse clinical practitioners because of the reimbursement but the people that I think are really suffering are the fee-for-service clinicians. It’s a terribly bad business model for them because not only are they on fee-for-service, at least at our place we can’t afford to pay people for no shows...they’re wonderful but they just don’t stay for long.

So, I do fee-for-service ... And it is completely unsustainable. I think I get reimbursed sort of the gross rate is $30 a session and I don’t get paid for no shows. When I calculate the time that I have to spend doing paperwork and attending meetings and just being there for someone doesn’t show up, I think it ends being closer to $15 an hour that I actually make. And I’m not going to be able to continue.... And I feel really sad that it won’t make sense for me to continue to stay there to provide care for the clients but it’s just not a sustainable model.

One provider mentioned the difficulty getting on insurance panels in the first place.
the MassHealth panels process is... we have a fee-for-service clinician who is still trying to go through the process and she’s been nearly a year in the process trying to get on the panel to be able to take on the MassHealth folks.

Low reimbursement rates driving decisions about practice sustainability
Most providers discussed reasons why they, and their colleagues, may decide to decline participation in insurance plans altogether. One provider mentioned an article he saw that stated almost 50% of psychiatrists didn’t accept private insurance.

... But I think the impact [of insurance authorization] is like... people decide not to take this insurance. But like for myself, doing fee-for-service work just isn’t sustainable.

... for someone in private practice, the rates offered by [plan]... are so poor that it is disincentive to see patients. And I may do that in any case because I want to continue to see my patients... from the clinic but it is an unfair burden.

... what I see happening is you have a three-tiered healthcare system. You have healthcare for the very poor, you have the MBHP [MA Behavioral Health Partnership] and then you have healthcare for those who can afford to pay out-of-pocket for psychiatric care. But... the vast majority of folks in the middle are squeezed because they have a harder time finding prescribers because a lot of prescribers, if they can opt out of taking insurance, they would prefer to do that because it often becomes more of a headache than a benefit. So, that’s one way I think it can affect the population’s access to psychiatric care because it takes away a service in great need and makes some of the providers feel, ‘why should I go through all this trouble if I can take payment out of pocket?’

A few providers mentioned frequent demands on their time that are not reimbursed.

...but when I worked at the clinic... it required a fair amount of time on the computer...that was the one very, very frustrating and routine kind of time-consuming thing that these authorizations had to be filled out in their entirety. ... if they require these forms...they should pay us for our time but... I don’t think they would do that. .......

.... I’ve spent half an hour, thirty-five minutes talking to one person after another... there’s no reimbursement whatsoever for this. So, it feels... it feels like they’re actually just driving people right out of accepting insurance.

... another casualty of the terrible reimbursement [is] that there’s no way to support team meetings or even staff meetings to share knowledge and to collaborate around people who are really struggling. I think that’s a real deficiency in the system.

I think reimbursement for phone sessions would be very important. Some of my patients can’t get up in the morning, they’re very depressed. If they can have a phone session, it would be very helpful.... I could make a phone call to them, we could talk, but I’m not reimbursed for that call so I’m disinclined to do it.

Several providers noted the impacts on coordination and quality of care, when these services are seldom if ever reimbursed, discussed in section VII.
One provider described the kinds of providers who can afford to take low reimbursement rates, and its impact on provider diversity.

I think for fee-for-service it’s an issue, you don’t earn enough to live off of… you end up [with providers from] … a particular demographic of which I’m in that have the partner [who can help support me]. And it means the people providing therapy aren’t necessarily going to come from the array that the patients are.

One provider described his/her clinic’s solution in managing low reimbursement rates.

...we have to insist that people who want to see psychiatrists in our clinic or clinical practitioners also see a therapist. So that means if someone is seeing a therapist in the community, they have a good relationship and they call us just for psychiatry, we can’t afford to provide it to them because the clinic loses so much money on the clinical practitioners. So, that’s why I think a lot of my colleagues I know have stopped accepting insurance altogether because the reimbursement is so terrible.

Low Reimbursement Rates by MassHealth
A few providers specifically mentioned the MassHealth reimbursement rates, provider burden, and the resulting effects on medically underserved communities.

MassHealth only pays for a third of what it costs to provide outpatient psychotherapy in my experience.

I think there’s kind of this cyclical effect...clinicians who really are invested in doing this work can’t, you know, to the point that was just made, can’t sustain that on the MassHealth reimbursement rate... That’s not feasible for many people, and it’s why many people do private practice and either bill to private insurances or don’t take insurances and just take private pay, because it’s more financially feasible ...I think that contributes to then there being a lack of services out in the community and the whole cycle just kind of continues?

Outside of the context of my clinic practice ...I can’t make ends meet and see the patient population that I would prefer to see. So, you know...as a somewhat more experienced clinician, I have no real ability to see the folks that I should be seeing.

... often times, in the community mental health setting, we’re working with people almost exclusively who have MassHealth, and they’re often people who have the most complex needs, who ... in the clinical sense really ought to be seeing a senior clinician, and the entire system of reimbursement completely makes the incentive structure upside down for trying to get them into a senior clinician, [with a] particular expertise area [or you want your patients to] have a relative expectation of continuity, because you don’t want to send somebody with a personality disorder into a therapy where they’re gonna see somebody for six months and then get transferred and transferred and transferred so... in my experience, [it’s] impossible to get somebody something that I would regard as clinically appropriate care.
XVIII. Consumer Challenges with Insurance

Challenges choosing health insurance plans
Most providers felt that consumers had little ability or capability to choose a health insurance plan that can meet their behavioral health needs.

...some patients don’t have a choice, and they have to have the insurance that the state chooses for them, and occasionally I’ve found that patients will find out when they get to our clinic that they have been switched to another piece of a MassHealth product without even knowing.

...most people ... are not considering or don’t know how to consider mental health benefits in choosing their plan. The people that do are people who are already in treatment and may need to be changing, or some change, so they’re already familiar with the system. Otherwise I think for most people they’re you know, they’re, um, the differences in plans, the different kinds of MassHealth plans are not all that dramatically different really about what they offer, and there’s no way of comparing, and for other people who are getting it from their employers, they don’t have a lot of choices.

... patients rarely if ever make decisions about their insurance. It’s usually the employers that make those decisions.

[It’s not a] matter of consumer choice, because at least in my experience, what we’re talking about is not so much like, differential relative merits of ...different particular products ... it’s that there are some people who are able to get what we would basically call medically appropriate care and a lot of people who just aren’t. And that they have no recourse.

One provider said that consumers’ sole focus on affordability may be especially problematic if insurance could be purchased across state lines in the future.

I suspect with the current political changes...People will be able to pick insurance policies from another state. ...And so I sense people will pick plans that they think are affordable to them, not knowing that some other state -- because I’ve seen this happen in some of the patients I have who have insurance policies in another state -- will limit some of their access to certain services that they won’t know about. And so I’ve seen that happen a few times in terms of medications, in terms of the copays, in terms of therapies.

Getting accurate information about participating providers
A few providers noted how the prevalence of “ghost panels” have a deleterious effect on consumers.

I think that the limited provider panels...make it ... difficult for people to have access ... So even though the insurance companies will say ‘oh we have plenty of people on our panel,’ the accessibility is not the case.

I have a patient ... and if you look on the website, there are no psychiatrists that are accessible to him. .... The websites are not up to date either so even if this person is also looking for primary care and has some paranoia, so it’s not easy. But the websites when we do look together...are not accurate and so you call and the person says ‘no, actually, that physician is not accepting MassHealth.’
The need for self-advocacy around appeals
Providers acknowledged that the need for self-advocacy during the appeals process is even more difficult for those with mental health or substance use problems.

…a lot of people … get discouraged easily, so they’re not necessarily that assertive or great advocates and even healthy people are not always that great. You know about pursuing appeal processes, especially lengthy appeals processes. Once they get discouraged, they don’t tend to go back to it.

... health insurance is predicated on a medical model of review...there is an appeals process, but that presumes that you have gallstones or thyroid cancer or type one diabetes, right? So, that presumes that you have a family safety net that is equipped to help you in this advocacy process, it presumes that you’re composes mentis, when you’re trying to appeal your need for care, it presumes that you’re not like drinking yourself to death or not living on a bench right? So … the people that we see very often are, to one degree or another, are uniquely compromised in their ability to advocate for themselves...an appeal process that’s patterned on the presumption that you’re basically a sensible person who’s operating at optimum mental capacity doesn’t follow for these patients.

.... if we think about the people who are most likely seeking these services....if you are cognitively compromised... if you’re living with major depression and ... if you’re struggling to function, it’s really hard to retain this information or to even think about [self-advocacy] because your brain just isn’t in that place, you’re not able to think as clearly ...

for some people, because they have a mental health condition and/or substance use concerns, you know, they’re less likely to be able to navigate that ....
Several providers discussed the need for better integration and coordination of physical and behavioral health care, as well as improved quality of care. A few providers noted that low reimbursement rates and other limitations made by insurance have a negative impact on coordination of care. Other providers mentioned their frustration with the lack of communication with other providers or even hospitals. Finally, a few providers discussed poor quality of care for people with mental illness and with substance use issues.

XIX. The Need for Better Integration and Coordination of Care

Poor continuity or coordination of care
Several providers noted that low reimbursement rates have a negative impact on coordination of care.

For one thing, there is no reimbursement or incentive for communication ... between people who are providing medical and behavioral health services...

I don't think it's accidental that it doesn't occur very much... they're not incentivizing, they say they want people to do it but ... that coordination of care doesn't occur. And it's not going to occur through electronic records.

I had to stop seeing children, because none of the incidental stuff that you have to do when you’re seeing children on an outpatient basis is covered by insurance even though general wisdom and prior research would seem to indicate that those things like attending IEP [Individualized Education Program] meetings and having regular conference calls with the parents and doing all those other kinds of stuff, it is critically important to the success of the treatment but they don’t pay for it, so I’d rather not see them then not provide the quality of care that I think is appropriate.

A lot of it sort of falls under the realm of interfacing with the school, interfacing with other providers. There’s a lot of legwork that you wind up doing when you see children if you want to do it properly and it becomes untenable.

So, in our practice, ... our 35 Suboxone patients and I see them free. They don’t get charged for a nurse visit here, there’s no co-pay, so often times the burden falls on me to see them [on a] regular basis to make sure that they’re getting access to their outpatient counselors ...

...you have [professionals] who come to the clinic and they’re wonderful but they just don’t stay for long. So as a result, the clients are faced with a pretty rapid turnover in their therapists after they’ve formed a good relationship ... [they have to] start all over again.
Other providers mentioned their frustration with the lack of communication with other providers or institutions.

I mean I have people that have gone to the hospital, I don’t hear from the hospital for, you know, I may get a report months later or something… so when people are getting care in one setting or simultaneously, there’s just a lack of any, on all levels, a lack of some discussion about what’s happening, that might be useful. Communication just doesn’t happen.

...if I have clients who’ve been to the emergency room, I hear about it from the client, I never hear about it from … a professional.

...being a small clinic that isn’t connected to a larger health system, it is really challenging to get in touch with providers and other systems…they can easily communicate amongst themselves but for us to get access to records or even to get a return phone call after multiple attempts, we’ll eventually give up. But I think something’s lost in not being able to cooperate more easily. … I cross agencies and I know that some of the larger ones are cross-collaborating but I think it leaves sort of independent small agencies sort of left out.

... they’re getting medication through their PCP [primary care provider], a lot of the time they have 2 or 3 different medications and they have no idea why they’re on what they’re on. The therapy, the dosage that they’re on … I waste a day trying to understand what is going on. I think, I really love the idea … I reach out, I email, I make calls, I very, very rarely get a call back. I understand they’re very busy but me being able to… I’m a social worker… I find it very hard to get the concrete information and a lot of the time when we do ask the question and it takes a while, you know, a lot of times the PCP has no idea what this person was given in terms of medication. But they took on the prescription from a psychiatrist who this person hasn’t seen in two or three years.

One provider mentioned the inherent problems with insurance covering detox services but no rehabilitation services.

...the fact that I can get people detoxed but can’t get them rehabbed, you know, it’s an ugly disease and it’s killing people, and just taking them out of the system isn’t going to fix anything, and I do as much education and trauma work with these people, it’s always dual diagnoses that I see, I think it is for everybody, and to not have that long term support or to have the longer term support be poor quality, you know, I can get someone into like a long term place and it’s really poor quality for MassHealth people.

**Poor quality of care**
A few providers felt that overall, there is poor quality of care for people with mental illness and with substance use issues.

In terms of inpatient psychiatric beds, a number of the people that I work with are … severely persistently mentally ill and… the quality of care that they receive in the inpatient units is highly variable once they even get there.

... I actually saw a patient yesterday and he was talking about where he was and it’s not clean and they don’t bring in meetings and it’s not what he thought, he’s not learning anything, he’s anxious…you know it’s not the first
time I’ve heard that about some places... there needs to be a strong focus on the healing. Not just the putting down the substance.

... and to be honest, the Suboxone centers that I’ve been dealing with, they’re... they’re not very patient-friendly or client-friendly. They’re not really interested in the welfare of their clients. It’s just... they run them in. There’s a huge amount of disrespect that I find that our center works hard to try to rebalance because a lot of folks... they just feel like they’re going up a hill. And these are meant to be agencies that are, you know, meant to be a support for them.
PROVIDER THEME 4: PARITY LAWS HAVE LITTLE IMPACT

During each group, providers answered questions about Massachusetts Parity laws and their impact on behavioral health care. While most providers had some awareness of and knowledge about parity laws, most felt that in practice, laws had little effect on ensuring equal access to care. In addition, few providers felt that consumer knowledge about these laws would help them in challenging insurance company denials.

XX. Awareness of and Knowledge about Parity Laws

While most providers had some awareness of and knowledge about parity laws, there were more than a few misconceptions about how these laws work. Most providers felt that in practice, laws had little effect to ensure equal access to care. A few noted the complexity of federal and state laws, making it extremely difficult for consumers to file a complaint of a parity violation.

...although there are federal parity [laws], I think each state can have their own way of defining it...

I’ve come across [this issue of parity] a lot, because I'm working with folks who are usually dealing with co-occurring disorders and so there are some things in terms of dealing with the medical system and all.

It’s just not happening, you know? Where are the beds? Where are the providers? It’s just not, it’s just not And, so they’re not getting the same opportunities. There's not a lot of parity, always. I'm not saying none, but... it's just not enough at this point.

They’re actually pretty complicated because they also depend on what type of insurance you have, whether the Massachusetts or the Federal laws apply, ... their differences and the size of the company, so it’s not a simple thing to sort of understand. But largely the idea is that ... insurance companies not discriminate what their medical benefits are from how their ... mental health...behavioral health benefits operate. So limits... exclusions for prior conditions... co-payments have to be relatively... comparable, but sometimes with different insurance companies, there are some limits that they may have on their medical end that you don’t know about until you inquire and so it’s not exactly an easy process to... make a... complaint about parity.

I think it’s hard for clients... the parity laws have to do with the kind of the equivalence of how mental health, substance abuse benefits and medical benefits are handled ... it’s complicated... clients need to know that there is a discrepancy... that’s different on the medical side than the [behavioral] health side. It’s just a really complex thing for clients to inquire about or understand.

... in terms of parity ... [these kind of problems don’t] seem like that would happen with something like physical therapy or radiology, but it happens in this field where treatment is questioned ... it sort of, even attempts to appeal it in order to prolong service are denied, and that’s really really challenging.

Most providers felt patients had little knowledge of parity laws. In response to whether patients are aware of parity laws, one provider quipped, "Why would they be?" A few
providers felt that increasing patients' knowledge about parity laws could be helpful in terms of self-advocacy.

I think in a way it can empower people, and take some of the stigma away, like, this is what's done, this has been done, you're gonna get the treatment you deserve, your diseases or whatever, are equal, we're going to get all this funding and we're going to treat this, but it doesn't work that way.

[Patients] often are given limited choices sometimes just one insurance and the company changes so... if information was made available to them and the company changes to a new insurance company, few people [could] go and read about how the healthcare parity law will affect this new company, especially if this company is based outside of Massachusetts.

I think some folks don't know anything about the parity laws. They just don't understand why is it harder to get psychiatric medications approved versus medical medications approved. And so because these are not often enforced, I don't even think there's any knowledge of what the rules [are] to me. It's tantamount to saying if there are no parking tickets for not parking and people won't really think you can't park at a certain location. I think the one issue is the lack of enforcement... And I think ultimately ... they're not knowledgeable about their rights...

Several providers lamented their own (as well as colleagues') lack of knowledge about the laws and their perceived inability to advocate for their patients because of it.

... I've been liaising with folks at Health Law Advocates and their training so I don't know the laws very well, but I understand that... there's a lot more processes involved in being able to check out why someone's being denied care. So I generally, I haven't learned more than that just 'cause I generally refer people to the Health Law Advocates folks and I probably should find the time to do it but I just... it seems to change quite a bit especially with the new law....

So a number of the folks that I work with, they're mental health counselors, they're social workers and I find myself very badly trying to tell them, you know, what I've heard about the laws so far. ... a lot of them don't have this knowledge and a lot of them have been in the field 20-30 years here in Boston and they don't even know about Health Care For All. So it's... there's a huge lapse with folks who taking health insurance. And so it's... I kind of was surprised at that.

I just want to say that I'm one of those people. I've been practicing for 40 years and I'm a medical director so I really should know more than I do. But the issue of parity doesn't really come up very much for me. I'm sort of embarrassed to acknowledge it but it's true.

...I don't even know what I don't know. I can't imagine what... I feel deficient in not being able to advise clients but I don't know what I don't know. I'm not sure what I would even advise them about.
PROVIDER THEME 5: STIGMA HAS A SIGNIFICANT EFFECT ON DELIVERY OF BEHAVIORAL HEALTH CARE

While providers did not discuss stigma in depth, some mentioned it as having a significant effect on care-seeking behaviors and the overall dysfunctionality of the behavioral health care system.

XXI. The Impact of Stigma on Care

Participating providers saw stigma as having a significant effect on care-seeking behaviors, what is perceived as a “real” illness, and the overall dysfunctionality of the behavioral health care system.

I think because people would rather have a severe medical illness, even seizure disorder, than a psychiatric diagnosis. Although often psychiatric illnesses can be much more treatable and can often have a much better prognosis. I’ve seen parents go through extensive demands of trying to find some clinical, medical explanation for why the child is having panic attacks as opposed to the fact that the child may have an anxiety disorder. So they come to us often very late after doing, you know, they want to look for chronic Lyme disease as opposed to school phobia.

...we really try to take a family approach and a lot of times the parent or family just wants the kid to be... “fixed” .... So ... it’s complex to not only explain family therapy and family dynamics and how they all contribute but also get everybody on board with participating and being open for change or even just discussion.

...there’s so much stigma around what we do with these people and there’s not a lot of funding for, there’s certainly not enough funding for mental health and substance use treatment. And that’s the problem. And I think the stigma, it plays a huge role, and that’s another huge barrier to access.

I think the disrespect that my clients have [received] ... going through the system, most of whom have been through other small outpatient counseling programs, and have been double booked or their counselor just disappears and no one does follow up.... And it all feeds into the stigma and... people would much prefer to have a heart attack or having a seizure disorder than having to deal with this because a lot of the visibility of it is very hard. People feel like they’re not being taken seriously as much. And if you’re throwing in substance use on top of that and any kind of pain issue, even more so that people are just not being taken seriously.

One provider felt there was a need to educate both the public and providers about the impact of stigma on care seeking behavior.

The American Medical Association views substance use as a disease, so it’s a chronic disease, so it helps... this is where that stigma comes in... [people say] "It’s just a bum on the street drinking, what are we gonna do?" ...And there’s so much shame, [for] the substance use population... there’s so much shame which prevents people from getting help and people are just dying all over the place and that’s gotta be part of the education [for outpatient providers]
PROVIDER THEME 6: VISION FOR THE FUTURE

XXII. Vision for a More Effective and Efficient Behavioral Health System

Both focus groups ended with a request to envision a better system for behavioral health care in Massachusetts. Providers mentioned insurance transparency, coordination of care, use of psychiatric preventative medicine, and the promise of behavioral health integration in Accountable Care Organizations.

Insurance company transparency

Providers felt that insurance companies should disclose more information about outcomes and cultural competency.

I’d really to see outcome measures for the insurance companies and if they’re going to practice in the space that they need to be able to ensure that they have adequate networks, that their networks are adequately reimbursed, that the paperwork isn’t unduly onerous and pointless. I’d really love to see more transparency in insurance practice.

…it would be great if insurance companies were more responsible to demonstrate the capabilities of their networks. And that includes linguistic and cultural richness. If there’s more transparency about the availability of insurance panels, practitioners of different linguistic capabilities or ethnicities, that would be great.

Coordination of care

Providers discussed the need for coordination of care that is reimbursable.

…when the patients or clients I’m working with are having a lot of trouble, what would be tremendously helpful is the ability to have a team meeting about this person. The therapist and the psychiatrist and the client and the family to actually sit together and talk together rather than all this peril at play.

I think if you have a team member whose job it is to try to coordinate care, I think it could really be helpful.

…we certainly work within a patient centered medical home model…being able to come see your PCP, meeting with a social worker, having easier access to med consult with a psychiatrist … having access to a community health worker, a health coach, any number of sort of supplementary roles that really create a full care team. So you’re not just seeing your doctor, you’re seeing a full medical team. …staff here feel really strongly about and are invested in. … there are still challenges… partly that is around the insurance and the reimbursement model.

Psychiatric preventative medicine

One provider talked about the potential of psychiatric preventive medicine.
The adult psychiatric consult... basically psychiatric preventative medicine. Like we could do a huge amount if we could get people admitted to inpatient or partial hospital situations, before it’s a catastrophe, so you know, so you can really nip a lot in the bud, you know. If you can, you know, if you can, if the private insurances that offer a certain number of covered visits a year basically no matter what, is an amazing model, and you could do a ton of preventative mental health care in that way, and, and, you know, with public insurance often you’re not really able to do that.

**Promise of integrating behavioral health through Accountable Care Organizations**

Two providers mentioned that ACOs could make a real difference in care.

... our agency is very interested in trying ... to prepare ourselves to be a health home for people with behavioral health issues. And we’re hoping also to be what is called a Certified Community Provider and in the accountable care organizations that are now emerging. ... it has required us to... learn the language and learn the culture and learn the priorities and values of more medically oriented organizations... and the biological oriented organizations. So, it’s been a bit of a culture strain and sort of values that strain for us. It’s also kind of alerted us that we have to probably do a much better job of demonstrating the value of the work we do in terms of demonstrative outcomes ...We work hard to have good relationships with the people we support. And if they’re happy, we’re happy. But we don’t really have metrics to demonstrate to insurers or accountable organizations or other similar organizations the actual value for what we do. So that’s had a pretty... a big impact on us.

As we move towards sort of a less of a fee for service model, hopefully, more of, you know we talked about patients centered medical home and ACOs, and I think as we’re moving more towards that model. My hope, my very tentative, tentative hope, is that insurance companies will be more invested, there is more investment in outcomes and in client outcomes, and so you know, that it might cost more to reimburse for things like collateral work, right, a lot of us talked about how people aren’t reimbursed, clinicians aren’t reimbursed for the amount of time that it takes to communicate with the school or the provider, or all of that sort of leg work, all that background work that’s crucial for care, for quality care. But if that were reimbursed, there might be more, it might be more expensive up front, but there would be longer term, ideally, patient outcomes. That the quality of care would improve long term.

...I think a lot of this comes down to pushing the insurance companies to accept more things, to reimburse for more things, like collateral care and things of that nature, but also to really advocate for them ...to accept ... services that they might see right now as sort of secondary or supplemental but are actually really crucial to care. So to me that’s one thing that would make a difference.

**Helping providers provide cost-effective, high quality care**

One provider felt that providers could help insurance companies pay for high quality care that is also cost-effective.
You know, one thing I would like to know as a provider is the cost of care. I know as we move into the ACO model, at least for MassHealth, I hope that this is something that they will share with provider groups and providers directly. Include us... we don’t want to break the bank. I don’t. ...If we were included in terms of the ... there’s been a little bit of this in terms of listing the cost of a medication compared to another one or a generic. ... But we should really be included in the overall cost of care and I’ve asked for this in some of the meetings that I go to, ‘Can we get a list that’s tantamount to the cost for member per month for this provider in terms of the overall cost that this member is accruing per month or per week for their overall care?’ So we can work as a team to think about how do we provide high quality care that’s also reasonable fiscally. I think most of us in training we’re not trained to sync that way. But I would be willing to think about the cost of care in terms of the overall benefit to the community as well as say you know what I know this is going to be more expensive, but I think the benefit to this patient outweighs the cost. Whereas this may be in the gray zone and so I’m wanting to try the less expensive option and see how it turns out. You know? So those are the kinds of things I’d be willing to try... If I can reduce their long-term side effects of the medication of the child or the person, I would prefer to do that and so to me the cost of the higher medication is benefitted by the long-term well-being of the patient.

Conclusion

HCFA’s focus groups with 42 consumers and providers provided some critical insights in coverage for, and access to, care for people with mental health and/or substance use concerns.

People with lived experience discussed several challenges finding and obtaining care, using health insurance, and managing costs. They also identified other issues, including inequities in behavioral health as compared to physical health care, and the impact of stigma in seeking care.

Across the two focus groups with providers, discussion focused around challenges providing care in an overburdened system, the negative impact of insurance on delivery of behavioral health care, and a sense that the “system” doesn’t serve the needs of people with behavioral health needs. They also discussed the inconsequential impact of parity laws on behavioral health care, the impact of stigma on delivery of behavioral health care, and what would make a more effective and efficient behavioral health care system.
APPENDICES
Types of Care Received (Consumers)
These are the types of care received by consumers both in inpatient and outpatient settings. The number next to each type of treatment highlights the number of consumers who utilized the service. Note: some consumers utilized more than once service.

Inpatient Unit
- Hospitalization (5)
- Residential Treatment Centers (4)

Outpatient (therapists, psychologists, psychotherapists, psychopharmacologists, social workers, clinical nurses)
- Individual Therapy (14)
- Group Therapy (5)
- Psychiatry (11)
- Detoxes (2)
- Rehabilitation (1)
- Partial hospitalization (2)
- IOP, or Intensive Outpatient Program (1)
- ECT, or Electroconvulsive Therapy (1)
- Primary Care Provider acts as psychiatrist (1)

Types of Care Offered (Providers)
These concern practice settings of participating mental health providers. The number next to the subcategories highlights how many providers work in each setting. For outpatient settings, services offered by participating providers are listed. Note: some providers practice in more than one setting.

Inpatient Unit
- Hospitalization (1)

Outpatient (individual therapy, psychiatry, substance use counseling, early recovery group, buprenorphine treatment, social work)
- Community Mental Health Practice (6)
- Solo or Group Practice (3)
- Hospital (1)
- In-home therapy (1)
FOCUS GROUP THEMES AND CODES BY FREQUENCY
This frequency table represents the frequency of quotes coded from the six focus groups transcripts. Blue represents consumer responses, while green represents provider responses.

THEMES AROUND CATEGORY 1: CARE

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- **(C-A-C):** Ability of a consumer to obtain care at an urgent moment of need. Key moment to connect consumer to services but there is often a lack of availability and the consumer must wait to obtain care.
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</table>
Have you or a family member tried to find treatment for alcohol/drug problems or mental health problems (depression, anxiety, etc.) in the past 3 years?

HEALTH CARE FOR ALL

Health Care For All wants to hear from Massachusetts residents like you!

Interested in joining the discussion?

- Participate in one of our **online** focus groups in October 2016 - all from the comfort of your home or office.
- Visit bit.ly/HCFA-1 and complete a quick survey to see if you qualify OR
- **Contact HCFA directly** at (617) 275-2897 or email hlipper@hcfama.org
- All participants will receive a **$25 Amazon Gift Card**

Health Care For All (HCFA) is a Massachusetts nonprofit advocacy organization working to create a health care system that provides comprehensive, affordable, accessible, and culturally competent care to everyone, especially the most vulnerable among us. We achieve this as leaders in public policy, advocacy, education, and service to consumers in Massachusetts. Learn more at www.hcfama.org. Having trouble getting health insurance? Call our HelpLine at (800) 272-4232.
Do you provide care for individuals with mental health problems or addiction concerns?

Health Care For All

Health Care For All wants to hear from Massachusetts providers like you!

Interested in joining the discussion?

- Participate in one of our **online** focus groups in October 2016 - all from the comfort of your home or office.
- Visit [bit.ly/HCFA-2](http://bit.ly/HCFA-2) and complete a quick survey to see if you qualify OR
- **Contact HCFA directly** at (617) 275-2897 or email hlipper@hcfama.org
- All participants will receive a **$25 Amazon Gift Card**

*Health Care For All (HCFA) is a Massachusetts nonprofit advocacy organization working to create a health care system that provides comprehensive, affordable, accessible, and culturally competent care to everyone, especially the most vulnerable among us. We achieve this as leaders in public policy, advocacy, education and service to consumers in Massachusetts. Learn more at [www.hcfama.org](http://www.hcfama.org).*
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<td>White</td>
<td>Yes</td>
<td>No</td>
<td>Adult</td>
<td>64</td>
<td>Female</td>
<td>Female</td>
<td>Some college</td>
<td>Full-time</td>
<td>&gt;30</td>
<td>Neighborhood Health Plan</td>
<td></td>
<td></td>
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<tr>
<td>26. Cambridge</td>
<td>White</td>
<td>Yes</td>
<td>No</td>
<td>Adult</td>
<td>40</td>
<td>Female</td>
<td>Female</td>
<td>Bachelors</td>
<td>Full-time</td>
<td>&lt;5</td>
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<td>27. Medford</td>
<td>White, H/L</td>
<td>No</td>
<td>Yes</td>
<td>Adult (F)</td>
<td>50</td>
<td>Female</td>
<td>Female</td>
<td>Masters</td>
<td>Full-time</td>
<td>21-30 yrs</td>
<td>Harvard Pilgrim</td>
<td></td>
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<td>Yes</td>
<td>No</td>
<td>Adult</td>
<td>53</td>
<td>Male</td>
<td>Male</td>
<td>Bachelors</td>
<td>Retired</td>
<td>&gt;30</td>
<td>MassHealth, Medicare, Tricare</td>
<td></td>
<td></td>
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<td>29. Malden</td>
<td>White</td>
<td>Yes (I+F)</td>
<td>No (I); Yes (F)</td>
<td>Adult (I+F)</td>
<td>46</td>
<td>Female</td>
<td>Female</td>
<td>Masters</td>
<td>Full-time</td>
<td>&gt;30</td>
<td>BCBS</td>
<td></td>
<td></td>
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<td>Yes</td>
<td>Yes</td>
<td>Adult</td>
<td>56</td>
<td>Female</td>
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<td>Associates</td>
<td>Part-time</td>
<td>&gt;30</td>
<td>UnitedHealthCare, Medicare</td>
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73
<table>
<thead>
<tr>
<th>PROVIDER LIST</th>
<th>Resident Of</th>
<th>Race, Ethnicity</th>
<th>Tx for MH</th>
<th>Tx for SUD</th>
<th>Age Group of Patients</th>
<th>Age</th>
<th>Sex (Birth)</th>
<th>Type of Provider</th>
<th>Practice Setting</th>
<th>Length of Practice in MA</th>
<th>Patient Characteristics</th>
<th>How do Patients Pay?</th>
</tr>
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<tbody>
<tr>
<td>1. Longmeadow</td>
<td>White</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Young Adults (19-25), Adults (26-64)</td>
<td>45</td>
<td>Female</td>
<td>Clinical Social Worker</td>
<td>Group Practice</td>
<td>&lt;5 years</td>
<td>All patients challenged by SU</td>
<td>In-network major private insurance plans, MassHealth</td>
</tr>
<tr>
<td>2. Somerville</td>
<td>Mixed Race</td>
<td>Yes</td>
<td>No</td>
<td>Some</td>
<td>Young Adults (19-25), Adults (26-64), Older Adults (65+)</td>
<td>28</td>
<td>Male</td>
<td>Clinical Social Worker</td>
<td>Solo Practice, Community Health Center/Community Mental Health Center</td>
<td>&lt;5 years</td>
<td>A few patients challenged by SU</td>
<td>Private Pay, In-network major private insurance plans, MassHealth</td>
</tr>
<tr>
<td>3. Boston</td>
<td>White</td>
<td>Yes</td>
<td>Some</td>
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<td>32</td>
<td>Female</td>
<td>Clinical Social Worker</td>
<td>Community Health Center/Community Mental Health Center</td>
<td>&lt;5 years</td>
<td>A few patients challenged by SU</td>
<td>MassHealth</td>
<td></td>
</tr>
<tr>
<td>4. Somerville</td>
<td>White</td>
<td>Yes</td>
<td>Yes</td>
<td>Child/Adolescent (0-18)</td>
<td>32</td>
<td>Female</td>
<td>Clinical Social Worker</td>
<td>Community Health Center/Community Mental Health Center</td>
<td>&lt;5 years</td>
<td>A few patients challenged by SU</td>
<td>In-network major private insurance plans</td>
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<td>5. Holden</td>
<td>White</td>
<td>Yes</td>
<td>Yes</td>
<td>Child/Adolescent (0-18), Young Adult (19-25), Adult (26-64), Older Adult (65+)</td>
<td>63</td>
<td>Male</td>
<td>Clinical Psychologist</td>
<td>Group Practice, Community Health Center/Community Mental Health Center</td>
<td>&gt; 20 years</td>
<td>A few patients challenged by SU</td>
<td>In-network major private insurance plans, MassHealth</td>
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<td>White</td>
<td>Yes</td>
<td>Yes</td>
<td>Adults (26-64)</td>
<td>51</td>
<td>Female</td>
<td>Nurse</td>
<td>Group Practice</td>
<td>&gt; 20 years</td>
<td>A few patients challenged by SU</td>
<td>In-network major private insurance plans, MassHealth</td>
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<td>7. Millis</td>
<td>Black</td>
<td>Yes</td>
<td>No</td>
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<td>54</td>
<td>Male</td>
<td>Psychiatrist</td>
<td>Group Practice</td>
<td>16-20 years</td>
<td>A few patients challenged by SU</td>
<td>In-network major private insurance plans, MassHealth</td>
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<td>8. Cambridge</td>
<td>White</td>
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<td>No</td>
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<td>Community Health Center/Community Mental Health Center</td>
<td>&lt;5 years</td>
<td>A few patients challenged by SU</td>
<td>MassHealth</td>
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<td>9. Lincoln</td>
<td>White</td>
<td>Yes</td>
<td>No</td>
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<td>69</td>
<td>Female</td>
<td>Psychiatrist</td>
<td>Solo Practice, Women's shelter</td>
<td>&gt; 20 years</td>
<td>A few patients challenged by SU</td>
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<td>67</td>
<td>Male</td>
<td>Psychiatrist</td>
<td>Community Health Center/Community Mental Health Center</td>
<td>&gt; 20 years</td>
<td>About half of patients challenged by SU</td>
<td>In-network major private insurance plans, MassHealth</td>
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<td>11. Quincy</td>
<td>White</td>
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<td>Yes</td>
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<td>Female</td>
<td>Clinical Social Worker; LADCII</td>
<td>Community Health Center/Community Mental Health Center</td>
<td>11-15 years</td>
<td>Most patients are challenged by SU</td>
<td>Private Pay</td>
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<td>PROVIDER LIST</td>
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<td>Race, Ethnicity</td>
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<td>Age Group of Patients</td>
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<td>Length of Practice in MA</td>
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<td>How do Patients Pay?</td>
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<td>12. Brookline</td>
<td>White</td>
<td>Yes</td>
<td>No</td>
<td>Adult (26-64)</td>
<td>61</td>
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<td>Solo Practice</td>
<td>&lt;5 years</td>
<td>A few patients challenged by SU</td>
<td>In-network major private insurance plans, MassHealth</td>
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</table>
CONSUMER GROUP MODERATOR GUIDE

[Introduction to Focus Group]

Hi everyone, my name is Hannah and I work for Health Care For All and I will be leading the discussion today. My colleague, Shahd, is also on the line and will be helping run the slides. On behalf of myself and Shahd, we would like to thank all of you for being here and for sharing your time and insight with us.

[Next Slide: Agenda]

Here’s the agenda for our discussion – I’m going to do a little bit of talking to run over some of the logistics of our conversation, we’ll do intros, and then we’ll dive into some discussion.

[Next Slide: About Us]

[About Us]

[Hannah refers to slide]

In order for us to better understand the experiences of people who have tried to access or have accessed mental health or substance use services, we need to hear from people like you who have a lot of knowledge within this field.

We are using information from our focus groups, as well as interviews and a survey, to inform how we can make changes to the behavioral health care system for Massachusetts residents like yourselves.

[Next Slide: Agenda]

[Next Slide: GoToWebinar]

[How GoToWebinar works]

- Before we get started with the our Focus Group I just wanted to do a quick run through of some of the logistics

- First, I want to point out that the way this program works is that everyone in attendance should be able to hear me either through their phone or through their computer’s speakers depending on which option they selected

- I will unmute all participants in this group, but please be conscious of background noise. Oftentimes, it’s helpful to put yourself on mute when you are not speaking to cut down on the background noise. Just remember to unmute yourself when you would like to speak.

- There may be times throughout this group where I’ll ask for a show of hands if something applies to you. If my question applies to you, you can click the little hand on
your panel and I’ll see that you’ve raised a hand. We’ll test it out now, so can everyone raise a hand by clicking their hand icon on the side of your screen? [Hand raise example] I’d also like to do this one by one so when I call your name, practice raising your hand [Hannah calls each name]

- There may be times where I ask questions through a poll as well. The questions will pop up on your screen during the focus group, please just select and submit an answer when this happens. We’ll test this out now [Shahd/Clare launch “what is your favorite flavor of ice cream” poll]

- As indicated in our consent form that you completed in our second short survey, this focus group will be recorded to help me capture all of the things we discuss. However, your responses will remain anonymous and no names will be mentioned in any of our materials or write ups after this group. We also ask that you keep fellow participants’ information private as well.

- If anyone has any technical difficulties during the focus group, our service provider, GoToWebinar, has a 1-800 number available for you to call with questions. That number is 1-855-202-7959.

  You can also call my colleague [Clare/Shahd/Kerry] directly and she can help you.

  If you’re having problems with this program, I just want to let you know that that’s absolutely okay – just listen in on your phone or through your microphones. The most important thing is that we can hear you.

- Lastly, as a thank you for your time, we are providing $25 Amazon gift cards to participants that complete our focus groups. We will be sending these gift cards to your emails on Friday, October 28th so look for these in your inboxes.

[Next Slide: Agenda]

[Next Slide: Guidelines]

[How today’s focus group will work]

1. Doing this over the phone can be really awkward for all involved. We obviously can’t read body language so it may be helpful to raise your hand icon if you’d like to speak. That way, we can make sure we get to you.
2. Speak up so we can hear you
3. Work for equal air time (we want to hear from everyone equally so be aware of how much or how little you’re talking)
4. None of us are professionals on these topics and understand that some of the things we talk about are sensitive, so there is no judgement from us and we ask that you remain
open as well. Also, we would like to steer clear from giving advice and ask that you do the same.

5. I may need to cut off discussions – I do not mean to be rude, this is just to keep our discussion moving along

6. Say what you believe or what you have experienced (even if others may not agree)

7. We’ll be speaking for 90 minutes; it’s okay to take a break to use the bathroom, grab a snack, and so on, but we ask that you are not away from the conversation for too long so we have enough discussion

As you can see on this slide, you all come from different backgrounds. I’m showing this because it’s important that I learn of how some of these differences have impacted your experiences. I may end of repeating the same questions regarding these kinds of details throughout our time together so this is a heads up as to why I may do that.

To dive right in, we’d like to hear more about some of the mental health/drug or alcohol services or treatments you all have accessed. Would anyone like to start?

[Discussion]

1. Reasons for not accessing care

Now we’re going to talk about potential reasons for not accessing care.

We have learned that a lot of people with mental health or alcohol or drug problems need care but never look for care. We would like to hear more about what prevents people from looking for services. [Shahd/Clare launch “What, if anything, prevented you from looking for care” poll] – Please take a second to select as many answers as applicable.

[Hannah writes down answers] – Shahd/Clare switch back to slide soon after showing results

i. Some of you answered with high costs. Can you elaborate on this (and also indicate if you’re talking about MassHealth, Medicare, or a private plan like Blue Cross Blue Shield)?
ii. Some of you answered with fear of what family/friends would think of me – can someone explain?

iii. How about for those of you who answered with worries about your health information remaining private – who can speak to this?

iv. [Other answers as needed]

[Next Slide: First experiences trying to find care]

2. Access issues

Let’s switch gears to talk about problems with accessing care.

So think back to when you realized you or your family member needed care for mental health and/or drug or alcohol problems. We’re curious to hear about your experiences first trying to find care. [Shahd/Clare launch “who recommended you get care” poll] – take a moment to select your answer or answers.

[Hannah writes down answers] – Shahd/Clare switch back to slide soon after showing results

i. So show of hands, who has tried to find mental health/drug or alcohol care within the past 3-5 years? 
   [PROBE: How did you find care? Did you go online? Call your insurance? Speak with your primary care provider?]

ii. What makes a good fit in finding a provider (like a therapist, psychiatrist, etc.)? What do or did you look for? 
   [PROBE: What qualities, good or bad, come to mind when thinking of your past or current behavioral health provider or providers?]

iii. Thinking back to all the mental health and/or substance use services you have used, were there easier ones to access?

iv. How do your experiences with access to mental health/sud services compared to your experiences with physical health services (like getting a check up with your primary care doctor or a vaccination)?

[Next Slide: Experiences paying for services]

3. Coverage issues

Now we’re going to talk about coverage issues.

I’d like to hear a little more about you/your family member’s experience getting a service covered/paid for by your health insurance plan whether MassHealth, Medicare, private plans,
or no insurance, etc. [Shahd/Clare launch “How would you grade your experiences getting your treatment paid for by your health plan” poll]

[Hannah writes down answers] – Shahd/Clare switch back to slide soon after showing results

i. After you tried to find care, what was your interaction with your insurance company? 
   [PROBE: What were some of the steps you took with your insurance company regarding getting your services paid for?]

ii. Show of hands, have you had problems getting a service covered? [Hannah counts hands]. How did you find out there was a problem?
   • What did you do about it?
     [PROBE: Call to complain, file an appeal?]
   • How was the problem resolved?
     [PROBE: Were the services paid for? Did you still receive care?]

iii. Some people learn about whether or not they had a service paid for through an “Explanation of Benefits” – which looks like this

[Next Slide: Picture of EOB]
Show of hands, has anyone seen one of these? [Hannah counts hands]. What were your thoughts about receiving a document like this?

[Next Slide: Services paid for by your health plan]

4. BH benefits

We’re going to shift gears a little and talk about your health plan’s benefits, which is a summary of what kinds of services your plan provides as well as how much you’ll have to pay for services. [Shahd/Clare launch “Have you heard of a Summary of Benefits and Coverage” poll]

[Hannah writes down answers] – Shahd/Clare switch back to slide soon after showing results

i. Show of hands, how many have read through their plan’s Summary of Benefits and Coverage? [Hannah counts hands]

[Next slide: Picture of SBC]

You can see on the screen an example of a Summary of Benefits and Coverage.

   [PROBE: For those of you who read through your plan’s Summary of Benefits and Coverage, what was your experience like? How about for those of you who didn’t read through this document?]

ii. Did anyone here have the opportunity to choose their health plan?
iii. Some people may choose specific health plans because they cover a particular service or even a certain therapist. What, if anything, influenced your choice in health plans?

iv. What do you wish you knew when choosing a health plan around behavioral health services?

[If No]

v. If you were choosing a health plan for your mental health or drug/alcohol needs, what kinds of information would you like to know?

[Next Slide: Agenda]

[Next slide: Wrap-up]

5. Wrap-up

We’re now heading into our closing questions.

i. In this discussion, we talked a lot about challenges with accessing care. Are there any other issues related to finding/accessing mental health and/or addiction care that should be discussed?

[PROBE: Compared to physical health?]

ii. We also spoke about experiences with insurance coverage, costs, and so on. Is there anything else to add to the discussion relating to insurance coverage of mental health and/or addiction services?

[PROBE: Compared to physical health?]

[Next slide: Thanks for sharing your story]

[Thanks for participation]

[Instruction about compensation]

To thank you for your time, you will be receiving a $25 Amazon gift card as promised. Your gift card will be sent to your email on Friday, October 28th.

[For any questions, contact Hannah]
Hi everyone, my name is Hannah and I work for Health Care For All and I will be leading our discussion today. My colleague, Margo Michaels, is also on the line and you may be hearing from her time to time. On behalf of myself and Margo, we would like to thank all of you for being here and for sharing your time and insight with us.

Here’s the agenda for our discussion – I’m going to do a little bit of talking to run over some of the logistics of our conversation, we’ll do intros, and then we’ll dive into some discussion.

In order for us to better understand the experiences of people who have tried to access or have accessed mental health or substance use services, we need to hear from providers who deal with these experiences every day.

We are using information from our focus groups, as well as interviews and a survey, to inform how Health Care For All can better advocate for needed changes to the behavioral health care system in Massachusetts.

Before we get started with the our Focus Group I just wanted to do a quick run through of some of the logistics

First, I want to point out that the way this program works is that everyone in attendance should be able to hear me either through their phone or through their computer’s speakers depending on which option they selected

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your panel and I’ll see that you’ve raised a hand. We’ll test it out now, so can everyone raise a hand by clicking their hand icon on the side of your screen? [Hand raise example] I’d also like to do this one by one so when I call your name, practice raising your hand [Hannah calls each name]

- There may be times where I ask questions through a poll as well. The questions will pop up on your screen during the focus group, please just select and submit an answer when this happens. We’ll test this out now [Shahd/Clare launch “what is your favorite flavor of ice cream” poll]

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  [Next Slide: Agenda]

  [Next Slide: Guidelines]

  [How today’s focus group will work]

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  9. Speak up so we can hear you

  10. Work for equal air time (we want to hear from everyone equally so be aware of how much or how little you’re talking)

  11. Some of the things we will talk about are sensitive, so there is no judgement from us and we ask that you remain open as well. Also, we would like to steer clear from giving advice and ask that you do the same.
12. I may need to cut off discussions – I do not mean to be rude, this is just to keep our discussion moving along
13. Say what you believe or what you have experienced (even if others may not agree)
14. We’ll be speaking for 90 minutes; it’s okay to take a break to use the bathroom, grab a snack, and so on, but we ask that you are not away from the conversation for too long so we have enough discussion

As you can see on this slide, you all have different professional backgrounds. I’m showing this because it’s important that I learn of how some of these differences have impacted your experiences as providers. I may end of repeating the same questions regarding these kinds of details throughout our time together so this is the reason why.

To dive right in, we’d like to hear more about some of the services or treatments that you provide. Would anyone like to start?

Now we’re going to talk about barriers to care.

We know that patients or clients experience a lot of different kinds of barriers to care. We’re interested in hearing more a little bit more about barriers to mental health/substance use care

i. In your experiences, what have been the greatest barriers your patients encounter in seeking care?
   [PROBE: What comes to mind when you think about access to care?]

ii. Along the same lines, what have been some of the greatest barriers to your providing quality care?

Now we’re going to talk about insurance policies and practices.
To start off, we’d like to know whether any of you are practicing or are moving towards practicing as part of a Patient-Centered Medical Home (PCMH), Accountable Care Organization (ACO), or Health Home. [Launch “do you currently practice or will you soon practice as part of a...” poll]

[PROBE: How, if at all, has this impacted your delivery of care?]

We’re hoping to hear everyone’s experiences specifically pertaining to health plans. We looked at this a little at the beginning of our discussion, I want to launch a quick poll for you all – [Clare/Shahd launch: How do your clients/patients pay for services?] – take a moment and select as many answers as applicable

i. For those of you who accept insurance, what has been your experience being on an insurance panel?
   [PROBE: For those not on insurance panels, what are some reasons for that choice?]

ii. We know that collaboration between providers and health plans is an important step in getting people the care they need. When you think of your experiences interacting with health plans on behalf of patients or clients, what comes to mind?
   [PROBE: What has been your experience with prior authorization or other utilization management requests?]

iii. I’m sure you’ve had clients or patients who had a service denied. What was your experience dealing with these denials?
   [PROBE: Did your client/patient appeal?]

iv. Keeping with the theme on insurance panels, an important part of your work is, of course, getting compensated. What has been your experience with reimbursement rates?

v. We’ve heard from a lot of stakeholders that there are some services within mental health and addiction care that should be reimbursed by plans but aren’t. What has been your experience with limits on services (whether on services that you’ve provided or experiences of colleagues)?
   [PROBE: How has this impacted your work?]

vi. Let’s brainstorm a little. What are some ways in which these experiences could be improved?

We’re going to switch gears a little to talk about your clients/patients experiences with their insurance.

vii. We know that some people choose (or wish they could choose) their health plans based off of the behavioral health benefits offered. What do you think patients/clients should know when/if choosing a health plan around behavioral health services?
viii. If you could change one thing about the information your patients/clients have for mental health/addiction services, what would it be?

[Next Slide: Parity]

3. Parity

Now we’re going to talk about how the parity laws relate to your work as providers.

i. How familiar are you with mental health parity laws? [Clare/Shahd launch: How familiar are you with mental health parity laws?] What do you know about them, (either Federal or Mass)? What are most of your peers’ awareness of parity?

ii. How about your patients/clients? [Clare/Shahd Launch: How familiar do you think your patients/clients are with the mental health parity laws?]

iii. What do you think your patients or clients need to understand about the parity laws?

[Next slide: Agenda]

4. Wrap-up

We’re now heading into our closing questions.

i. In this discussion, we talked a lot about that challenges that you and your patients/clients face with either providing or accessing care. Are there any other issues related to finding/accessing mental health and/or addiction care that we should discuss?

ii. We also spoke about challenges created by insurance policies or practices and how they’ve influenced you in your work. Is there anything else to add to the discussion relating to insurance coverage of mental health and/or addiction services?

iii. Looking towards the future, what is one thing worth changing about the current system that would help you better provide care for individuals with mental health and/or addiction needs?

[Next slide: Thanks for sharing your story]

[Thanks for participation]

[Instruction about compensation]

To thank you for your time, you will be receiving a $25 Amazon gift card as promised. Your gift card will be sent to your email tomorrow.

[For any questions, contact Hannah]