

Patient and Family Perspectives on Accessing and Continuing Behavioral Health Services: A Qualitative Investigation

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Abstract

Many individuals seeking behavioral health treatment struggle to establish care. Attrition from treatment is also common. There is reason to be concerned that vulnerable populations face disproportionate barriers to accessing and sustaining care. The factors contributing to these phenomena are not well understood. The authors report the findings from focus groups and individual interviews with adults who have received behavioral health treatment and others who were family members of individuals who had received behavioral health treatment. Forty-five individuals insured by Massachusetts Medicaid (MassHealth), as well as 25 family members of those seeking treatment, participated in these sessions, 15 of them with Spanish interpretation. Facilitators sought to identify and elucidate modifiable facilitators and barriers to care. Four themes were identified by analyzing transcripts of these sessions. These themes were: preferences for demographically concordant clinicians; barriers and facilitators to care navigation; the importance of patient-centered clinician behaviors and strong therapeutic alliance; and the benefits and risks of family involvement in treatment engagement. Policy recommendations to address barriers and facilitators to treatment are reported.

Keywords: access; retention; engagement; Medicaid; mental health treatment; substance use treatment

Introduction

Unmet behavioral health needs

In the United States, one in five individuals are living with behavioral health (BH) conditions. Millions more are impacted by symptoms but have not received treatment. (Substance Abuse and Mental Health Services Administration, 2021). BH conditions include mental health disorders, such as depression, anxiety disorders, and post-traumatic stress disorder, and substance use disorders, such as alcohol or opioid use disorders (Committee on Strategies to Improve Access to Behavioral Health Care Services through Medicare and Medicaid et al., 2024). Despite the high prevalence of these symptoms and conditions, many individuals struggle to access care due to system-level and environmental barriers, including limited-service availability; inadequate clinician training; untimely, costly, or unavailable transportation; and insurance coverage issues (Adams, 2025; Derr, 2016; Gunlicks-Stoessel et al., 2025; Morain et al., 2022; Stein et al., 2018; Tuck & Smith, 2019).

Difficulties establishing care

The high demand for BH services and the simultaneous shortage of clinicians makes it difficult for many individuals to establish care. In communities where services are available, many individuals seeking treatment continue to experience significant difficulties in navigating the healthcare system and accessing services (Adams, 2025; Armoon et al., 2025; Davenport et al., 2023; Gunlicks-Stoessel et al., 2025). Prior research has attempted to describe the factors impacting individuals' ability to access services. One review of cross-cultural barriers to care identified four factors that make it difficult to establish care including the individual's cognition, affect, values, as well as physical or structural barriers (Leong, 2011). Stigma is also consistently identified as contributing to individual's reluctance to engage in care (Clement et al., 2014). In addition to stigma, studies of adolescents and young adults have identified low levels of mental health literacy and a preference for self-reliance as contributing to low motivation to engage in treatment (Gulliver et al., 2010; Lui et al., 2024).

Premature termination of care

Once individuals initiate BH services, many discontinue care early in treatment, often before improvement or remission of their symptoms (Barrett et al., 2008; McGovern et al., 2024; Roos & Werbart, 2013). A literature review identified factors such as psychotropic medication non-adherence, individual level attitudes and behaviors

(e.g., substance use, perceived stigma), treatment characteristics (e.g., medication side-effects, long treatment duration), lack of social supports, healthcare system-related factors (e.g., lack of free access to medicine, healthcare clinician shortages), and medication/transportation costs as those associated with discontinuing treatment (Semahegn et al., 2020). There is evidence of lower engagement and retention in treatment among racial/ethnic minorities (Acevedo et al., 2018; Maura & Weisman de Mamani, 2017; Mennis et al., 2019).

Disparities in access to care

Mental health and substance use disorder treatment access issues are more pronounced for individuals from marginalized racial and ethnic groups (Cook et al., 2017; Lagisetty et al., 2019; Olfson et al., 2023). Additionally, there is concern regarding the impact of stigma towards BH treatment and a perceived lack of cultural humility among clinicians, yielding distrust among those seeking care (Findling et al., 2022; Lekas et al., 2020; Misra et al., 2021; Mosher et al., 2017).

Disparities in access to care have also been found to be associated with geographic- and state-level factors (Cummings et al., 2017; Sun et al., 2023). Geographic, payer, and racial/ethnic factors frequently overlap, and compound each other, creating even greater barriers for some individuals. Initiatives to improve access to services for racial and ethnic minorities have demonstrated modest improvements. For example, programs that bridge primary care and specialty care services have demonstrated promise (Asarnow et al., 2015; Interian et al., 2013). Payer-based initiatives to decrease barriers to accessing treatment and promote ongoing engagement in treatment are needed. In Massachusetts, stakeholders have recommended increasing the diversity of the BH workforce with the goal of creating a service system that reflects the diversity of those in need (Lipson et al., 2022). Many of these overlapping barriers converge in the Medicaid program, which is the largest single payer for BH services in the United States (Tuck & Smith, 2019). Medicaid members experience BH conditions at disproportionately high rates, making barriers to establishing and sustaining care especially consequential for this population (Tuck & Smith, 2019).

Study rationale and objectives

Although prior studies have described barriers to establishing and sustaining BH care in the general population, less is known about how Medicaid members experience these barriers, and the perspectives of the

family members who support them are rarely reported. Direct accounts from members and their families can identify modifiable barriers that are not apparent in administrative data. Given the barriers and facilitators noted in the literature and our goal to expand our understanding of these factors in relation to the specific needs of individuals insured by the Massachusetts' Medicaid program (MassHealth members), our study had two primary aims. The first aim was to characterize the lived experiences and perspectives of individuals who had attempted to initiate BH treatment for themselves and the experiences of family members who were supporting a relative with BH needs. The second aim was to describe the facilitators and barriers to sustaining engagement with BH services once care had been established. In the Discussion, we summarize our findings to offer member and family-informed insights into modifiable barriers that Medicaid policy and system redesigns have the potential to address.

Methods

Setting

MassHealth is the Massachusetts Medicaid and Children's Health Insurance Program, covering children, adults with low incomes, seniors, and people with disabilities. During the study period, from November 2021 to February 2022, MassHealth covered approximately two million people, about one in four Massachusetts residents. Enrollment was rising throughout this period under the federal continuous coverage requirement in effect during the COVID-19 public health emergency and exceeded 2.2 million members by April 2022. Children made up 36% of the membership, and adults and children with disabilities were 15% of members (Massachusetts Medicaid Policy Institute, 2022). MassHealth is a payer rather than a provider of care. Members receive services from community health centers, hospital systems, community mental health centers, and independent clinicians. MassHealth members reflect the diversity of the Commonwealth across race and ethnicity, disability status, sexual orientation, and gender identity (Massachusetts Medicaid Policy Institute, 2022). MassHealth covers treatment for mental health conditions and for substance use disorders. For this study, the geographic region of MassHealth members was derived from their zip code and assigned to one of the six MassHealth regions of the state (Northeast, Greater Boston, MetroWest, Central, Southeast and Cape, and Western). The behavioral health conditions reported by participants were mental health conditions alone or a substance use disorder with or without a co-occurring mental health condition (Table 2). The MassHealth behavioral health system has changed substantially since these data were collected, as described in the Limitations section.

Participants

Data collection was completed between November 2021 and February 2022. Our study sample included two stakeholder groups: (1) MassHealth members (i.e., patients; 18 years or older) who had received or were currently receiving BH treatment within the prior year; and (2) family members/caregivers of MassHealth members that had received or were currently receiving BH treatment within the last year. For this study, BH treatment was defined as treatment for a mental health disorder and/or a substance use disorder. The registration form included two screening questions, one confirming a diagnosed BH condition and one confirming BH treatment within the prior 12 months. Registrants who answered no to either question were excluded and did not complete the remaining registration questions. Individuals not enrolled in MassHealth, and those under 18 years of age, were also excluded. Family members and caregivers were eligible if the MassHealth member they supported met these criteria, whether or not that member also participated. Participants registered and were scheduled in one stakeholder group, either as a MassHealth member or as a family member. Whether a participant also occupied the other role was not systematically ascertained, so the two groups may overlap to an unknown degree.

Measures

Semi-structured interview guides. Two guides were developed, one for MassHealth members and one for family members and caregivers. The guides were not derived from a published conceptual framework. They began as a set of high level questions about access to and continuation of BH treatment, drafted by the evaluation team based on the aims of the evaluation, and were then built out in parallel so that both stakeholder groups were asked about the same domains from their own vantage point. Development was iterative and took place between July and November 2021. Feedback was incorporated from the full evaluation team, two expert clinical consultants, and representatives of MassHealth's Office of Behavioral Health. Both guides covered pathways into BH treatment and the referral process, initial experiences of treatment, communication between BH clinicians and a member's other health care clinicians, family involvement in care, clinician preferences including language, race and ethnicity, and sexual identity, workforce availability and diversity, barriers and facilitators to continuing treatment, and privacy and information sharing. The member guide also asked about telehealth and about how family and friends regarded the member's treatment. The family member and caregiver guide also asked about the caregiver's own role in the member's care, including how that role changed over time and instances in which a caregiver intervened to promote

a member's engagement in treatment. Before data collection began, the family member and caregiver guide was rehearsed in mock sessions in November 2021, and notes from those sessions produced revisions to question wording, question order, and probes in both guides. The full evaluation team attended the first few member focus groups, each of which closed with a debrief to fine-tune questions and prompts. Both guides were drafted in English and translated into Spanish by bilingual staff at the authors' institution. Copies of both guides, in English and in Spanish, are provided as Online Resources 1 to 4.

Procedures

Recruitment. Recruitment flyers and a registration form (Qualtrics, Provo, UT) were developed in English and Spanish. A website address to the registration was included on all recruitment materials, as well as a quick response (QR) code. The study was reviewed and approved by the authors' Institutional Review Board; written informed consent was waived. A \$50 gift card was provided to both member and family member focus group (FG) participants. A fact sheet explaining the study and reminding participants of their rights was sent to all selected participants prior to the FG.

Multiple recruitment strategies were employed to obtain a diverse sample including both purposive and snowball sampling. Our team worked to increase representation of Spanish-speaking members, so a higher percentage were invited. Purposive sampling was used to recruit participants through several channels, including distribution of recruitment flyers to relevant listservs, outreach to colleagues working in primary care settings across Massachusetts, and posts on social media. To support recruitment of a diverse sample, participating members, family members, and interested clinicians were also given recruitment materials to share through snowball sampling.

Registration forms collected demographic information from members and family members including year of birth, gender, race/ethnicity, and zip code. The registration form asked what accommodations a participant would need in order to take part, including American Sign Language interpretation, Communication Access Real-time Translation, help with Zoom software, interpretation or written materials in a language other than English, and breaks during the session. Participants who were not comfortable using Zoom software were sent written instructions in advance, were offered assistance from a team member, and could take part by telephone instead. Contact information was collected to schedule participation. Members had the option of including a family

member's contact information so they could be invited to register. Members and family members were selected from the registrations using quota sampling to obtain demographic breadth across age, gender, race/ethnicity, and geographic region. Quotas were set on these demographic characteristics rather than on the balance between the two stakeholder groups, and no target number was set for members or family members. Registration and participation were individual, and although a member could supply a family member's contact details for an invitation, members and family members were not recruited or paired as dyads. Reasons for non-participation were not collected. Registrants who were not selected were not contacted further, and selected participants who did not attend were not followed up. No participant took part in more than one session.

Scheduling and conducting focus groups. Up to five MassHealth members and family members at a time were selected from the registration and invited to each FG. Sessions attended by only one invited participant proceeded as individual interviews using the same guide. Two bilingual English and Spanish speaking consultants assisted in responding to project inquiries and scheduling. Spanish-speaking members and family members were scheduled into focus groups separate from English-speaking participants, and one of the two consultants co-facilitated all of those groups. These groups used consecutive interpretation in which the lead interviewer asked each question in English, the consultant interpreted the question into Spanish and then interpreted participants' responses back into English. Fifteen of the 70 members and family members (21%) participated with interpretation. FGs were conducted by one lead interviewer from the evaluation team and one or two other team members to co-lead, assist with logistics, and take notes. FGs were scheduled for 90 minutes and took place remotely over Zoom. Each FG participant was provided with the fact sheet. FGs were audio-recorded with the permission of the participants. Gift cards were sent via postal mail following FG participation.

Research team and reflexivity

The evaluation was carried out by a health services research and evaluation team at an academic medical center under contract to the state Medicaid agency. The team comprised two clinical psychologists, one health services researcher, and three research coordinators, all of whom had prior training and experience in qualitative research. Focus groups were led by a licensed psychologist, with one or two additional team members present to co-lead, assist with logistics, and take notes. Two expert clinical consultants advised on the design of the guides, and

two bilingual English and Spanish speaking consultants supported scheduling and provided interpretation. No member of the team had a prior clinical, professional, or personal relationship with any participant, and no member of the team had any role in participants' eligibility for MassHealth or in their access to behavioral health services. Participants were told at the start of each session that the purpose of the discussion was to bring their experiences to the attention of MassHealth, and that neither their names nor other identifying information would be shared with MassHealth or with their clinicians. The evaluation team comprised five women and one man. All six team members self-identified as White and none spoke Spanish. The team therefore did not share the racial or ethnic background or the language of many participants. The Spanish-language sessions depended on the bilingual consultants. Several practices were used to surface and check the team's own influence on the data. A team member took notes during every session. Each of the first member focus groups was followed by a full team debrief, and debriefs continued through the data collection period as a standing item in team meetings.

Analysis

Transcription of recordings. A reputable vendor was used to create verbatim transcripts from audio recordings. Transcripts were quality assurance checked and uploaded into the mixed-methods software, Dedoose (v 9.4), for qualitative analysis.

Coding of transcripts. We analyzed the transcripts using an inductive thematic analysis following the principles outlined by Patton (2015) for the design, conduct, analysis and reporting of qualitative studies. Codes were derived from the data rather than from a prior conceptual framework, a shared code book was developed and applied by two coders working independently, and intercoder agreement was assessed as a check on the consistency with which codes were applied. Initial code development drew on established grounded theory coding techniques, but the study did not adopt a grounded theory design and we did not seek to generate theory. Using well established protocols for coding qualitative data, four evaluation team members reviewed the transcripts independently to create an initial set of codes (Glaser & Strauss, 1967). This process was guided by a careful review of the interview guide to ensure representation of all relevant themes discussed by participants. A draft code book was developed from this initial process. Team members met regularly to review select excerpts, discuss code applications, and create additional codes on an iterative basis until the code book was finalized. Members and family members were coded with the same code book and analyzed together, with codes summarized within and across the two groups.

Two evaluation team members served as primary coders for all transcripts. An initial transcript was selected and coded independently by each of the two primary coders. The two coders then came together to review code applications. Inconsistencies were discussed, and revisions were made to the code book as needed. This process was repeated until the two coders reached an inter-rater reliability (IRR) level of greater than 80% across select transcripts. The final codebook was uploaded to Dedoose. Transcript coding was done independently by the two coders. The lead evaluator provided oversight and input where consensus/decision-making was needed and to ensure codes were applied consistently.

We do not report the number or percentage of participants endorsing each theme. The interview guides were semi-structured and their questions open-ended, so not every participant was asked every question in the same way, and a count of who raised a topic would reflect the flow of each discussion as much as the distribution of experience. Focus group data compound this, because an apparent consensus within a group is a property of the interaction rather than a sum of the individual views held in the room, and the strength of an opinion cannot be read from how often it was voiced (Acocella, 2012; Sim, 1998). We therefore describe the relative prominence of findings using consistent verbal descriptors, reporting a finding as shared by nearly all, most, many, some, or a few participants, or by one participant, and we make no claim about the prevalence of any experience beyond this sample. We use “nearly all” to mean all but one or two of the participants who spoke to a topic, “most” a clear majority of them, “many” a substantial share short of a majority, “some” a minority larger than a few, “a few” two or three participants, and “one participant” a single voice.

We did not assess data saturation. Recruitment was governed by the evaluation’s fixed data collection window and by quota sampling designed to obtain demographic breadth across age, gender, race/ethnicity, and geographic region, rather than by a judgment that no new information was being contributed. Twenty focus groups and five individual interviews were conducted. We make no claim that the themes reported here exhaust the range of experience among MassHealth members and their families. Transcripts were not returned to participants for comment or correction, and participant feedback on the findings was not sought. The final code book is available from the corresponding author on request. A completed Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist is provided as Online Resource 5.

Results

Participant characteristics

Twenty focus groups and five individual interviews were conducted between November 2021 and February 2022. Just over half (56%) of registrants were invited to participate, of whom 72% participated. A total of 45 MassHealth members and 25 family members participated. The rates of participation were similar for English and Spanish speaking members (Table 1).

Table 1
Recruitment and Participation

	Registrants ^a	Invitees ^b (% of registrants)	Participants ^c (% of invitees)
Respondent type^d			
MassHealth members	123	64 (52%)	45 (70%)
Family members	51	33 (65%)	25 (76%)
Primary language^d			
English	139	75 (54%)	55 (73%)
Spanish	35	22 (63%)	15 (68%)
Overall	174	97 (56%)	70 (72%)

^aRegistrants – individuals who submitted their registration form

^bInvitees – registrants invited to participate in a focus group or interview

^cParticipants – invitees who participated in a focus group or interview

^dCounts are reported separately by respondent type and by primary language. The two are not cross-tabulated.

About one-fifth (21%) of participants used Spanish interpretation in the FGs and interviews. Two-thirds (66%) of MassHealth members and family members self-identified as female and more than half (54%) self-identified as non-White or of more than one race. There was representation across the six regions of the state, collapsed to three groups in Table 2. Twenty-nine percent of participants reported a substance use disorder with or without a co-occurring mental health condition (Table 2).

Table 2

MassHealth Member and Family Member Demographics

	Characteristic	N (%)
Current Diagnosis		
	MH	50 (71%)
	SUD with or without MH	20 (29%)
Age Group		
	45 years and younger	29 (42%)

	46 years and older	40 (58%)
Gender		
	Male	23 (33%)
	Female	46 (66%)
Race/Ethnicity		
	White or Caucasian (non-Hispanic)	32 (46%)
	Non-White (non-Hispanic)	13 (19%)
	Hispanic	25 (36%)
Geographic Location		
	Greater Boston	26 (37%)
	Eastern (not Greater Boston)	19 (27%)
	Central and Western	25 (36%)
Primary Language		
	English Speaking	55 (79%)
	Spanish Speaking	15 (21%)

Note. Funder’s regulatory requirements mandate that all demographic categories must contain at least 11 individuals. To meet this requirement, participants reporting a substance use disorder alone and those reporting both a mental health condition and a substance use disorder are combined in a single category. Age is reported in two groups, collapsed from the five adult age bands used in the parent evaluation, and geographic location in three groups, collapsed from the six MassHealth regions, because the smaller categories did not meet this requirement. One participant reported a gender other than male or female, and that category is suppressed under the same requirement. Age was not reported for one participant, so percentages for age group are based on 69 participants; percentages for every other characteristic are based on 70.

In 2021 and 2022, approximately 46% of Massachusetts Medicaid enrollees were White and non-Hispanic, 28% were Hispanic, and about one quarter were non-White and non-Hispanic (KFF, n.d.). The sample matched the population estimate for White, non-Hispanic participants (46%) but over-represented Hispanic participants (36%) and under-represented non-White, non-Hispanic participants (19%), the over-representation consistent with recruitment that included Spanish-speaking members. These estimates come from a household survey rather than enrollment records, so the comparison is approximate.

Four themes were identified in the experiences shared by participants. Percentages of respondents endorsing each theme are not reported, for the reasons given in the Analysis section. Each theme is reported below with its sub-themes, and Table 3 provides one exemplar quotation for each sub-theme.

Table 3

Exemplar Quotations by Sub-theme

Sub-theme	Exemplar quotation
1a. Difficulty finding demographically concordant clinicians, and occasional success	“My son, he’s been requesting a male therapist and there’s none out there ... What I hope for when we walk in is for my son to feel comfortable. You know what I mean? Engage. Because it’s hard, I mean, to start with a new person, you feel... He’s a kid, he’s like, ‘Oh, here we go again.’ But what I hope for is for him to be able to feel comfortable in that first meeting. Because if it’s not there, he’s not going back.” (Family member, Q1)
1b. Directories and referral guides omit clinician demographics	“I also was in search of a therapist for couples therapy recently and I was relieved to find a therapist of Asian descent, which is also my background and my partner’s background. And we feel that this individual can possibly understand our cultural norms a bit better than someone of non-Asian descent... I did that also through the online website... It was the name was the hint... And then looking further in, we saw the languages that that individual spoke and that confirmed it.” (Member, Q2)
1c. Limited workforce diversity discourages and delays engagement	“I fear that once he turns 18, that he’s just going to make the decision not to get services anymore, that’s been playing in my mind a lot. Again, I’m a single mom. I’m Hispanic, I’m Puerto Rican, and his dad is African American. I wanted to mention that because there’s also a lack of minority counselors out there. So, I feel that he was to find a good minority man therapist, that that would help him, man figure, someone that he can relate with. It’s hard. A lot of the therapists are white females, so he has a hard time trying to relate with them.” (Family member, Q3)
2a. A confusing, discouraging search, with outdated and inaccurate information	“So I’ll read like the whole MassHealth packet and everything that like comes with it. So I’m aware of that. But people that are just like not understanding what’s even in their coverage... when I tried to actually do it online it was a hassle like trying to navigate finding one on my own... it was very confusing and most of them were not up to date I want to say... So definitely that being user-friendly, there being like a user-friendly way to just find someone in your area or even identifying which ones serve telehealth versus in-person would be great. Because I know that’s specifically important to some.” (Member, Q4)
2b. Care pathways are often built for crisis and court-ordered care	“And then, of course, it wasn’t until the first hospitalization that I really started getting all kinds of help and people just started to take me seriously.” (Member, Q5)
2c. Resources and dedicated pathways that help,	“So, the intensive care coordinator kind of took the role of figuring out what services to put in place in the home or in the community, and the family partner was in place to kind of support me as a mother in navigating support and resources in the area. And they were very

Sub-theme	Exemplar quotation
including navigators and care coordinators	instrumental, I have to say, and actually led me to get into the field myself, so now I support families looking for those types of services. So, it was very helpful to have that person kind of facilitate getting those services in place and educating me in terms of what was available out there, so that's how we originally started with getting our services is through an ICC." (Family member, Q6)
2d. System-level facilitators and disruptions: scheduling flexibility, telehealth, coverage lapses, and financial assistance	"For behavioral health, I love the telehealth stuff. Obviously, because we're not talking medical, so I won't go on about that. But I think the one thing is, is I have established providers so I don't mind doing the telehealth with them." (Member, Q7)
2e. Clinician turnover as a system-level disruption	"Trying to find somebody like a skills trainer or a therapeutic mentor was very difficult for us because what we would find is we'd get somebody in place after a long wait and then the person wouldn't stay. Because either my son's issues were too complex for them or they weren't comfortable or maybe they were young and inexperienced and they just couldn't handle it." (Family member, Q8)
3a. Demeanor, communication, and "fit" shape engagement in both directions	"I think that what makes a good first visit is somebody that's actively listening to what's going on. They're not asking question after question but sort of like really trying to understand and empathize with what's going on in my current situation." (Member, Q9)
3b. Need for clinician patience, especially after trauma	"She actually questioned and I listened to her. I listened to her also because she was asking me about my background and who I was, and she was listening. She also was telling me a little bit about her, and I felt like she was doing that to get me to talk more. Because I only told her so much in my first visit. And so after that first visit... I kept opening up a little bit more and a little bit more." (Member, Q10)
3c. Preference for experienced clinicians, flexibility, self-disclosure, and genuine engagement	"My therapist saw that I was in the hospital for a cardiac issue, and she's like, 'Well, you've had a very difficult time this week. Is it okay if we meet, or do you want to skip this week?' That amount of consideration and care, it's really encompassing. Versus somebody who's very removed and doesn't know what's going on." (Member, Q11)
3d. Harms associated with lengthy, repetitive, impersonal intake assessments	"I just felt very dismissed. It was like an intake type of thing as well. I just find that it's very, almost dehumanizing in a little bit of a way. People ask about really sensitive stuff but in a way that isn't like considerate of how I'm feeling about it." (Member, Q12)
4a. Families as practical and emotional facilitators	"My parents play a pretty integral part in my treatment. My dad actually packs my pills. He initially got me involved with the department of mental health. He got me involved with who to call from MassHealth. They got me my providers initially. I got my own primary care physician.

Sub-theme	Exemplar quotation
	But in terms of mental health, they've been the advocates for me.” (Member, Q13)
4b. Involvement seen as necessary for children and adolescents	“I always ask the therapists that are working with my kids, like, ‘I know that whatever you talk with them is confidential, but is there any way that I could know how to help them while they’re at home, or if they need to do something different for school, that we could know so that way we are able to help them? Because if we don’t know, we won’t be able to do it.’” (Family member, Q14)
4c. Some participants expressed desire that their family members be invited into treatment	“Right now what I’m going through, I have mentioned it to my therapist and to my psychiatrist, what my son is going through. And not once have they said, ‘Well, you know what? Bring him here when you come so I can talk to him.’” (Member, Q15)
4d. Risks of family involvement: adverse experiences, loss of autonomy, and exclusion	“When I came into recovery, I’m doing it for me. I’m not doing it for my family, or my best friend, or nobody. I’m doing it for me. And I wanted it to be about me. I didn’t want no outside interference with that. So, I objected to that. I didn’t want my brother or nobody.” (Member, Q16)

Theme 1: Preferences for demographically concordant clinicians

1a. Difficulty finding demographically concordant clinicians, and occasional success

Participants reported that individuals with BH needs struggled to identify clinicians that met their preferences. Most participants who looked for a male, non-white or Spanish-speaking BH clinician described difficulties finding a clinician or noted a disparity in the workforce. In contrast, some participants shared positive experiences with a clinician of their preference. For example, they were able to find a clinician that matched their preference with regard to age, gender, race/ethnicity, or sexual orientation/ LGBTQ+ identity, “Well, my daughter... is transgender...we were able to find someone who was transgender to be on her team.” (Family member, Q17)

1b. Directories and referral guides omit clinician demographics

One participant reported having to infer details of a clinician’s demographics, specifically race, based on the clinician’s name and the languages the clinician was listed as speaking. Referral guides and directories were cited as rarely providing this information to those seeking services.

1c. Limited workforce diversity discourages and delays engagement

Limitations in the diversity and representation of the BH workforce were identified as significant factors that discouraged initiation and continuation of treatment and often contributed to delayed engagement in services.

Theme 2: Barriers and facilitators to care navigation

2a. A confusing, discouraging search, with outdated and inaccurate information

Many participants expressed intense frustration when discussing the process of finding a BH clinician and initiating treatment; describing the process as confusing, difficult, and discouraging. Misinformation in the form of outdated resources and inaccurate referral information was also reported.

2b. Care pathways are often built for crisis and court-ordered care

Participants shared having frequently sought BH treatment following a traumatic or life-altering event. Participants described their first connection to treatment as often following a hospitalization, mental health crisis, drug overdose, or incarceration. This finding raises concerns that those in need of care are often not connected to treatment until their symptoms are relatively severe, and their risk of death is high. Another path to treatment was described as being court-ordered to receive BH treatment through social service agencies.

2c. Resources and dedicated pathways that help, including navigators and care coordinators

Participants also listed resources used to find clinicians, including online resources (e.g., MassHealth website), static information (e.g., a printed directory) from MassHealth or healthcare clinicians, community health groups, community organizations or support groups (e.g., Parent/Professional Advocacy League), referral service agencies, care coordinators, and others with lived experience (e.g., family members, teachers, etc.). Some participants with specific conditions such as HIV, a developmental disability, or an opioid use disorder, described dedicated treatment pathways that existed for those conditions. These treatment pathways often included a patient navigator or other practical assistance in initiating and sustaining treatment. When problems emerged, these support services helped individuals avoid gaps in treatment.

2d. System-level facilitators and disruptions: scheduling flexibility, telehealth, coverage lapses, and financial assistance

Flexibility with scheduling and telehealth services were identified by many as facilitators of treatment initiation and continuation. Lapses in MassHealth coverage for some participants contributed to difficulties

remaining engaged in treatment. In some cases, participants reported benefiting from financial assistance which helped them access and remain in treatment.

2e. Clinician turnover as a system-level disruption

Some participants expressed frustration with clinician turnover and cited it as a contributor to disengagement from care. Participants reported frequently experiencing clinicians beginning and ending relationships too quickly for the member to benefit from treatment.

Theme 3: Importance of patient-centered clinician behaviors and strong therapeutic alliance

3a. Demeanor, communication, and “fit” shape engagement in both directions

Focus group participants reported that clinician behaviors had the potential to impact engagement in treatment positively or negatively. Many participants had described negative experiences with clinicians for reasons related to their demeanor, communication, level of experience, or simply because they were “not the right fit.”

3b. Need for clinician patience, especially after trauma

Clinicians who demonstrated patience (i.e., not “rushing a process”) were well regarded by most participants, and this behavior was noted as promoting engagement. This was especially true for those participants who had experienced a history of trauma.

3c. Preference for experienced clinicians, flexibility, self-disclosure, and genuine engagement

Many participants expressed a preference for experienced clinicians as well as those who were flexible in their approach to scheduling encounters, for example providing evening and weekend appointments. Some participants cited a clinician’s willingness to disclose their own personal experiences with BH concerns as contributing positively to a participant’s engagement in treatment. Alternatively, clinicians who were unwilling to disclose details about themselves were seen as less desirable by some participants. A related concern heard from participants was a perceived lack of engagement by clinicians, meaning that participants did not feel their clinician was genuinely seeking to connect with them. This lack of collaboration contributed to premature discontinuation of treatment.

3d. Harms associated with lengthy, repetitive, impersonal intake assessments

Nearly all participants who described having received assessments from clinicians expressed frustrations with lengthy, repetitive, and impersonal assessment processes at the beginning of treatment or when seeing a new

clinician. One member described such an assessment and its consequence: “She asked me a lot of questions about my family background, my existing support system, and told me that this was for her own evaluation in a 45-minute session. And so I felt overwhelmed and found myself crying at one point in the session. And she didn’t check on my emotions or feelings in that, even though it was evident that I was somewhat emotional and overwhelmed. And I just felt that her objective was for information-gathering... And so leaving that session, I don’t feel like I’m going to continue with her and go with her services.” (Member, Q18)

Theme 4: Benefits and risks of family involvement in treatment engagement

4a. Families as practical and emotional facilitators

Families were described by many as playing an important role in participants’ ability to access and remain engaged in treatment. Family involvement often facilitated transportation, medication management, scheduling, and improved satisfaction with treatment.

4b. Involvement seen as necessary for children and adolescents

For family members of young children and adolescents, their involvement and role in the participant’s treatment was seen as necessary and an important component to the treatment itself.

4c. Some participants expressed desire that their family members be invited into treatment

Some adult participants noted that they would have liked to have been offered the opportunity to include their families in their treatment sessions. Likewise, some family members reported that they would like greater involvement in the care of their family member, or the opportunity to communicate to clinicians about the care of their family member. This was particularly true for those participants who had multiple co-morbidities and other pertinent health concerns who might have needed assistance with medication adherence, for example.

4d. Risks of family involvement: adverse experiences, loss of autonomy, and exclusion

However, the impact of family involvement was highly variable and, in some cases, seen as a negative factor in initiation and retention in treatment. Some participants reported particularly adverse experiences with family involvement in treatment. This was especially true when the individual in treatment experienced a loss of autonomy with regards to treatment. Some participants noted that they would prefer not to have their families involved in their treatment due to dysfunctional or strained relationships and concerns about their family members’ potentially negative impact on outcomes. Although family involvement was mostly noted as having a positive

impact, or a potentially positive impact, there were some cases where participants and their clinicians chose to exclude family members from treatment.

Discussion

This study examined the perspectives of MassHealth members and their family members on accessing and remaining in BH care, with the goal of identifying modifiable barriers and facilitators. Analysis of focus group and interview data revealed four cross-cutting themes: preferences for demographically concordant clinicians, barriers and facilitators to navigating a complex treatment system, the importance of patient-centered clinician behaviors in establishing therapeutic alliance, and the benefits and risks of family involvement in treatment engagement. These findings illuminate how both structural factors and clinician behaviors impede access and retention in treatment. Participants proposed system and clinician-level changes to address these barriers, including workforce diversification, the increased availability of care navigation, expanded scheduling flexibility, and greater insurance stability. These recommendations are consistent with the existing literature on BH access and treatment engagement.

Alongside these consistencies, this study contributes in three ways. First, family members were recruited and interviewed directly about their own efforts to support a relative's engagement in care, rather than as proxies for the members they support. This study builds on prior reviews that examined family involvement as a practice within mental health services, drawing on service users (Cameron et al., 2023) and on service users, families, and providers together (Tham & Solomon, 2024). Because the members and family members in this study spoke about the same treatment system, the benefits and the risks of family involvement can be described from both sides of the same relationship. Second, as described below, participants valued clinician concordance not only in race and ethnicity but also in gender identity and sexual orientation, dimensions that remain understudied. Third, participants described the full treatment pathway within a single state Medicaid program, so that barriers usually studied separately appear here as they accumulate for the same individuals.

Participants reported difficulty establishing care with clinicians who shared their identity (race, ethnicity, gender, sex, etc.) and associated these difficulties with contributing to lower rates of engagement. This finding is consistent with literature showing the importance of shared gender, racial, ethnic, linguistic, or cultural backgrounds

between patients and clinicians. A recent overview of systematic reviews on racial and ethnic concordance in mental health found that concordance tends to have a greater positive effect for Black clients than for other racial and ethnic groups and that matching can assist in building therapeutic rapport, particularly early in treatment (Jackson et al., 2025). Shen et al. (2018) found that racial concordance was associated with better communication. These findings reinforce the recommendation, advanced by Alegria et al. (2016) and Maura and Weisman de Mamani (2017), that diversifying the BH workforce is one strategy for improving treatment engagement among minority populations. A novel contribution of this study was participants' extension of these preferences beyond race and ethnicity to include gender identity and sexual orientation, a dimension of concordance that remains understudied in the literature.

An absence of culturally responsive communication was identified by participants as a factor that discouraged engagement in care. This is consistent with a systematic review by Aggarwal et al. (2016) which found that clinicians can improve treatment initiation and continuation for racial and ethnic minority patients by incorporating patient's personal understanding of illness, using tailored language, addressing stigma, and demonstrating positive affect.

Participants frequently reported that their first connection to behavioral health treatment occurred only after a hospitalization, mental health crisis, drug overdose, or incarceration event. Consistent with our finding, a systematic review of care pathways for Black individuals with first episode psychosis found that entry to specialty services was often delayed and frequently involved law enforcement contact (Oluwoye et al., 2021). Research has also found that coercive experiences such as involuntary psychiatric hospitalization can damage trust in clinicians, reduce willingness to disclose symptoms in subsequent encounters, and thereby further disrupt pathways to voluntary care (Jones et al., 2021).

Patient navigators were identified as a valuable resource for supporting the initiation and retention in treatment by participants, who described a preference for continuity of care with patient navigators with condition-specific expertise. A scoping review of navigation programs for individuals with mental health and substance use concerns identified barrier reduction, client-centered support, and integrated care as critical activities which improved outcomes for individuals experiencing these issues (Mullen et al., 2023). An overview of 11 systematic reviews of patient navigation in ambulatory care similarly found that patient navigators expanded access to health

services, particularly for vulnerable and underserved patient groups, by providing education, counseling, translation, and appointment facilitation (Budde et al., 2021).

Participants in our study described clinician patience, flexibility, willingness to self-disclose, and genuine engagement as shaping whether they remained in treatment, and a perceived absence of genuine engagement as a reason for leaving it. A meta-analysis of 295 psychotherapy studies representing more than 30,000 patients found a moderate, positive association between therapeutic alliance and treatment outcome ($r = .28$) (Flückiger et al., 2018). The relationship between alliance and premature dropout is particularly relevant to the concerns raised by participants in our study. A separate meta-analysis of 11 studies found a moderately strong relationship between therapeutic alliance and dropout ($d = .55$); weaker alliances predicted premature discontinuation in this study (Sharf et al., 2010). Consistent with participants' experiences in our study, a meta-analytic review found that therapeutic alliance was significantly associated with therapist empathy ($r = .50$) and genuineness ($r = .59$) (Nienhuis et al., 2018).

Preferences for clinicians with more experience, greater scheduling flexibility, and a willingness to disclose personal experiences were reported by participants. These findings align with a general finding that patients who receive their preferred type of treatment demonstrate significantly lower dropout rates (Windle et al., 2020). Additionally, some participants cited clinician turnover as a contributor to their disengagement, reflecting a broader systems issue that adversely impacts therapeutic relationships, thereby contributing to dropout.

Study participants identified clinicians' attitudes and behaviors as major contributors to disengagement from treatment. Participants described an absence of accurate empathy, acceptance, positive regard, and genuineness in their encounters with clinicians. These behaviors are shaped by the conditions in which clinicians work. A qualitative study of a state public behavioral health workforce identified low wages, documentation burden, and poor administrative and physical infrastructure among five themes that negatively affected clinicians' workplace experience and retention, with large caseloads contributing to worker stress (Hallett et al., 2024). Mental health clinicians themselves report that the behaviors that follow from these conditions, including disengagement and diminished empathy, can compromise the therapeutic alliance (Harrod et al., 2025). These conditions contribute to clinician turnover and make it difficult for clinicians to consistently provide the interpersonal care participants seek.

In our study, participants' views of family involvement were varied. For some, family support was associated with improvements in accessing and sustaining care. For others, family member involvement was reported as adverse. Consistent with these findings, a systematic review of patients' perspectives on family involvement in mental health care found that benefits and harms were both reported, that preferences for involvement were highly variable across individuals, and that a more nuanced and individualized approach to involving families is needed (Cameron et al., 2023). A scoping review of barriers to family involvement in routine services for individuals with severe mental illness found that clinicians' privacy concerns frequently contribute to families being excluded from care (Tham & Solomon, 2024).

Participants' accounts suggest that these barriers were not encountered one at a time. Spanish-speaking participants described searching for a clinician who spoke their language, a search narrowed by the small number of such clinicians, while also meeting the outdated and inaccurate referral information that participants described more generally. Family members seeking care for children and adolescents with complex needs described a similar accumulation, waiting for a placement, assembling services across more than one agency, and then losing clinicians who did not stay or who were unprepared for those needs. In both accounts, the difficulty arose not from any single barrier but from multiple barriers occurring together. These co-occurrences reflect participants' descriptions rather than an analytic assessment of intersections, as themes were coded separately and not examined for overlap.

Strengths and Limitations

Strengths of this study include a recruitment and selection strategy designed for breadth. Participants were recruited through purposive and snowball sampling and were then selected from the registrations using quota sampling across age, gender, race/ethnicity, and geographic region, which produced a sample with diverse experiences from across Massachusetts. Additionally, participants shared a wide variety of lived experiences with mental health and substance use disorders and diverse settings in which they received treatment. Finally, 15 of the 70 participants took part through Spanish interpretation, so the sample was not restricted to English speakers.

Limitations of this study include challenges recruiting participants from specific marginalized groups, such as immigrants from Asian countries. By its nature, qualitative research is subjective, despite efforts to standardize interpretation and inter-rater reliability coding of qualitative analyses; it is possible that our methods suffered from

biases that we were unable to control. An additional limitation of this study was the reliance on recruitment via electronic messaging, social media, and email. This may have systematically excluded participants who are underrepresented on these platforms.

Additional limitations in our study should guide interpretation. First, the modest gift cards may have attracted participants whose views differ from those of other MassHealth members and families. Second, focus groups are vulnerable to social desirability bias. Participants may have restricted their contributions to topics they perceived to be acceptable to other participants or the evaluation team, and they were speaking about a program that paid for their care, to researchers working on that program's behalf, which may have discouraged some criticism. Third, all participants were MassHealth members or their family members living in Massachusetts, a state with a relatively well-resourced behavioral health system and an expanded Medicaid program. Barriers and facilitators may differ for Medicaid populations in other states. Fourth, focus groups were conducted over videoconferencing software. This format allowed participation from across the state but required a device, a reliable high-speed internet connection, and a private space. These requirements may have excluded individuals with limited access to technology or privacy. Fifth, behavioral health conditions carry stigma, and some participants may have withheld experiences they considered too sensitive to share in a group setting. Sixth, participants took part in one stakeholder group according to how they registered, and dual roles were not ascertained, so some participants counted as family members may themselves have been MassHealth members receiving behavioral health treatment, and the reverse. The two perspectives we report may therefore overlap more than the design implies. Finally, the focus groups took place between November 2021 and February 2022, during the COVID-19 public health emergency and before the launch of Community Behavioral Health Centers and the post-emergency MassHealth eligibility redeterminations. The experiences described here reflect the system as participants encountered it at that time rather than the current MassHealth behavioral health landscape.

Implications for Research and Policy

Our findings point to modifiable barriers that Medicaid policy and system redesigns have the potential to address. Clinician training, supervision, and continuing education that prioritize accurate empathy, positive regard, genuineness, and cultural humility may improve engagement in treatment (Miller & Moyers, 2021). Training

clinicians in these principles, alongside accountability for their implementation, may support more consistent delivery of relationship-centered care. Administrative requirements that prioritize data collection over rapport building during initial encounters should also be reconsidered. Reimbursement rates, caseload expectations, and documentation requirements shape whether clinicians can practice these skills, making adequate compensation and staffing part of the same problem rather than a separate one. Continued diversification of the BH workforce may improve treatment engagement among minority populations, and dedicated patient navigation with condition-specific expertise has the potential to improve outcomes for patients with unmet BH needs. Earlier, non-crisis access to care may prevent the erosion of trust that can follow adverse experiences with crisis-driven entry into treatment. One route to earlier contact is integrated behavioral health in primary care, which has been associated with improved access to outpatient care (Leung et al., 2019), with lower emergency department use among adults with behavioral health conditions (Maeng et al., 2022), and with improved behavioral health outcomes for children and adolescents (Asarnow et al., 2015). Finally, policies that promote collaboratively negotiated family involvement would recognize families as a factor that can either promote or discourage engagement and retention in care.

This study advances our understanding of the barriers to accessing and sustaining engagement with BH services for a Medicaid-insured population. Future research should focus on the extent to which policy changes have addressed the issues identified by members and family members. The launch of Community Behavioral Health Centers (CBHCs) in Massachusetts in 2023, after the study period, represents a significant structural reform that is distinct in important ways from the federal Certified Community Behavioral Health Clinic (CCBHC) framework (Petrovsky et al., 2025). Research is needed to evaluate whether these approaches address the access and engagement concerns raised by participants in the present study. Specifically, researchers should examine whether the no-wrong-door approach and the family integration features of CBHCs have improved patients' experiences and outcomes. Additionally, efforts to diversify the BH workforce must be rigorously evaluated to identify effective and scalable strategies, as national data suggest that concordance between clinicians and the populations they serve in underserved areas remains uneven across racial and ethnic groups (Baker et al., 2024). Finally, there remains an open question about how best to promote clinicians' use of skills that strengthen the therapeutic alliance; without attention to this fundamental concern, structural reforms alone will be insufficient to increase engagement and retention in BH treatment.

Conflicts of interest statement

The authors declare that they have no conflicts of interest related to the content of this manuscript.

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