It leaves me feeling defeated:
Searching for in-network mental health care with marketplace insurance

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Public Agenda

Overview

How difficult is it for people with marketplace insurance to find in-network health care providers, and how do delays and challenges in accessing care affect people's lives? This report is based on in-depth qualitative research that followed seventeen people covered by insurance plans purchased on state and federal marketplaces as they tried to find in-network mental health care providers.

None of the seventeen participants managed to schedule an appointment with an in-network provider that took place during the study, even though sixteen of them had been searching for providers even before the study began. They found the search process to be complex, time-consuming, and frustrating. Participants reported that searching and delays in getting care negatively affected their mental health, relationships, work or school, physical health, and finances. To increase access to mental health care, participants wanted insurers to cover more mental health care providers and to make out-of-network providers more affordable. They also wanted more streamlined processes for identifying in-network providers and to eliminate the need for referrals for mental health care.

The participants in this study were searching for mental health care providers because they had newly identified a need for mental health care, because they lost their employment and had to purchase coverage that their existing providers did not accept, or because the no-cost therapy sessions available under their existing plans ran out. Participants answered weekly structured prompts from October 11 to November 14, 2022, as they searched for providers, tried to figure out which were in network, obtained referrals when needed, and tried to schedule appointments.[1] A companion study followed people covered by marketplace plans as they tried to find and schedule appointments with in-network diabetes care providers. The methodology section of this report provides more information about how this study was conducted.

Key findings

1. **None of the seventeen participants managed to schedule an appointment with an in-network provider that took place during the study.** Sixteen of the participants had already been searching for a mental health care provider prior to the start of this study, including five who had been searching for six or more months. But none of them were able to schedule an appointment with an in-network mental health care provider that took place during the study.

2. **Six participants scheduled appointments, but only two believed that the mental health provider would be in network.** Two participants scheduled appointments with mental health care providers that took place during the study. One of them knew the provider would not accept their insurance. The other believed the provider was in network, only to find out later they were not. Both had to negotiate prices for their out-of-network care. A third participant scheduled an appointment but had to cancel because the provider did not accept her insurance and she could not afford to pay out of pocket. Another three participants scheduled appointments that would take place after the study period. Two of them believed the provider would be in network, while the third was not sure whether or not they would be in network or not.

3. **The six participants who scheduled appointments had to make tradeoffs in order to do so.** Of the six who scheduled, three believed they would have to wait too long for their appointment. One would have to travel over ninety minutes for their appointment. As noted above, only two believed that the provider they scheduled with would accept their insurance.

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[1] While this project was designed to illustrate the experiences of these participants as they searched for a mental health care provider, the challenges they encountered, and how delaying medical care for their mental health affected different aspects of their lives, it was not designed to be representative of everyone's experiences finding a mental health care provider.

4. **The most commonly cited challenges in searching for mental health care were a lack of in-network providers and a lack of appointments available at workable times.** Nine of the seventeen participants said they experienced difficulties finding a mental health care provider who accepted their insurance, including four who indicated it was a "chronic challenge," i.e., they experienced it multiple weeks in a row during the study. The only other challenge cited as often was difficulty finding providers with appointments at workable times.

5. **Searching for in-network mental health care providers or delays in getting care negatively affected all participants, impacting their mental health, relationships, work or school, physical health, and finances.** Most participants said their relationships with friends and family were affected, either because they diverted time from relationships to searching for mental health care or because worsening mental health symptoms strained relationships. Participants also reported challenging search processes and delays in getting it impacted their work, with some reporting losing their jobs or missing out on income. Even participants who scheduled appointments reported negative effects of searching and delayed care. Five participants were impacted across all five domains.

6. **For all participants, whether they scheduled or not, trying to find in-network mental health care was time-consuming, requiring them to piece together information across a variety of sources and speak with multiple providers.** Participants' described a continuous cycle of attempting to identify providers, understand their benefits, figure out whether providers were in network, obtain referrals, and book appointments. Some had to wait weeks for insurers or prospective providers to respond to questions or for appointments. Participants who had to obtain referrals from primary care physicians found that process time-consuming and frustrating, and questioned whether referrals should be necessary.

7. **Among the eleven participants who were unable to schedule appointments, few were confident they would find the right provider for them.** Only two of the eleven who were unable to schedule were confident that they would find a mental health care provider who would be a good fit for them. The other nine were concerned about finding providers who were affordable, in convenient locations, had workable appointment times or who would be good fits culturally, linguistically, or interpersonally.

8. **Participants wanted better ways to identify in-network providers, questioned the necessity of referrals, and wanted insurers to cover more providers.** Despite having access to their insurer's directories, participants expressed a need for centralized, easy to find, accurate information that would help them identify in-network providers. Some participants suggested that referrals should not be required for mental health care because obtaining them prolongs the search process, creates stress, and necessitates scheduling and waiting for expensive primary care appointments. Many expressed a need for insurance networks to include more mental health care providers or at least offer some coverage for out-of-network care.

For more information about this study, go to **https://www.publicagenda.org/reports/netad-2023/** or contact **research@publicagenda.org**.

Before the study, most participants had already spent time and faced challenges searching for mental health care providers. Most had already been negatively affected by the search process.

All seventeen participants were covered by insurance plans purchased on state and federal marketplaces. Thirteen of them were looking for providers either because they had newly identified a need for mental health care—typically due to recent stressful or overwhelming life events—or because they were not satisfied with the care that they had received from a previous provider.[2] Four were searching for new mental health care providers because they either lost their employment and had to purchase coverage that their existing providers did not accept or because the no-cost therapy sessions available under their existing plans ran out.

Only one participant mentioned that her primary care physician had recommended that she find a therapist. No other participants mentioned that a health care provider had recommended they seek mental health care.

"I have had two miscarriages this year and that has been hard to deal with. When I mentioned depression to my primary care provider after my dad died in 2016, she suggested I take a twenty-minute walk outside every day, so I haven't been back to her. I also tried online pharmacies/ NP/PAs. They gave me Effexor which made me SO SLEEPY that I couldn't function during the day, so I stopped taking that. I just don't know what to do next." Vicky, white, in her 30s, Texas[3]

"I have dealt with major depressive disorder, generalized anxiety disorder, ADHD, and PTSD since I was 19 years old. Depending on what is currently going on in my life, the symptoms of these illnesses can debilitate me and keep me from being productive and healthy. After a brutally tumultuous divorce from a man who was emotionally and fiscally abusive, I moved [to a new state]. Obviously, I have some issues from the aforementioned situation to address and recover from." Sharon, white, in her 40s, Alabama

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2   One participant was searching for a mental health care provider for both herself and for her son. The rest were searching only for themselves.

3   Quotations have been minimally edited for clarity. The names used in this report are pseudonyms. The photos are representations and are not actual images of the participants.

> *"I'm trying to find a mental health provider because I feel that there are issues from my past as well as the present that I need to address. Most of them have to do with military service and the state that the country is in when it comes to racism and inequality."* Vince, Black, in his 50s, Alabama

> *"I was downsized from my employer and lost my insurance coverage. Signed up for coverage through the ACA marketplace. My doctor does not accept my new coverage, so I've had to find a new doctor."* Howard, white, in his 50s, Florida

> *"I am looking for a mental health person because I get off track. I have anxiety a lot and recently I've been hurt due to an operation, and I've just been really depressed, down, thinking stupid stuff sometimes. My insurance gave me a free therapist that lasted only six weeks."* Cathy, Black, in her 50s, North Carolina

Prior to the study, five participants had already been searching for a mental health care provider for six or more months. Eleven had been searching for at least one month. Only one had not searched at all in the previous thirty days. Nine of the participants had spent three or more hours searching over the thirty days before the study began.

Fifteen participants were looking for either a psychologist or psychiatrist. Some indicated they were also interested in finding a counselor or social worker. Two participants indicated they were looking for whatever they could find.

Steps in searching for mental health care providers:

✓ **Identify prospective providers:** Participants reported looking for names of mental health care providers and checking to see if prospective providers accepted their insurance. They also tried to find information that could help them figure out if the provider would be a good fit for them.

✓ **Understand coverage:** A few participants tried to figure out what type of mental health care would be covered by their insurance plan, how many sessions would be covered, and what their payment responsibilities would be.

✓ **Contact prospective mental health care providers:** Many participants called prospective providers to ask for information such as whether they were they accepting new patients, when the next available appointment was, and to find out how much they would have to pay out of pocket.

✓ **Obtain referrals:** Prior to scheduling an appointment, many participants needed to see their primary care physician (PCP) to get a referral. This required them to contact their PCP to schedule an appointment, go to an in-person appointment, get a referral, and send it to a prospective mental health care provider.

Seven of the seventeen participants had used two or more types of sources to search for mental health care providers before the study began; see **Figure 1**. In addition to trying to identify prospective providers before the study, participants reported that they had already looked for information about how their insurance coverage worked, requested referrals from primary care physicians, and contacted prospective mental health care providers.

Before the study, insurers were the source most often used to identify prospective mental health care providers.

Figure 1. Number of participants who said, prior to the start of the study, that they had used each of the following to identify prospective mental health care providers:

👤👤👤👤👤👤👤	7	**Insurers**
👤👤👤👤👤👤	6	**Friends and family**
👤👤👤👤	4	**Online searches**
👤👤	2	**Primary care providers**
👤👤👤👤	4	**Other sources or not defined**

Base: All participants, N=17.
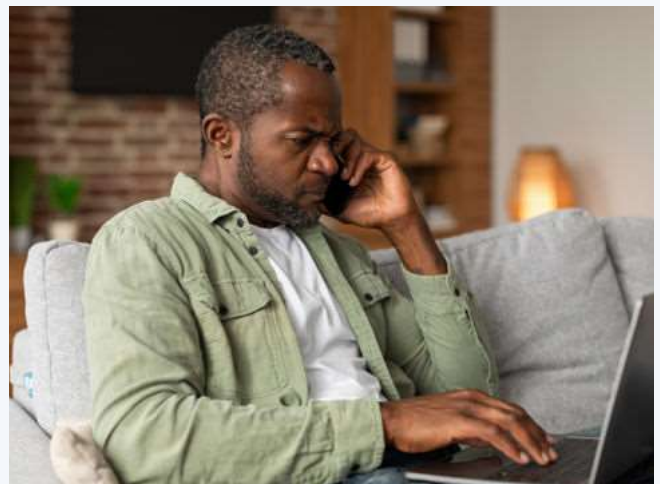
Prior to the study, all but one participant had already faced at least one challenge in searching for mental health care provider. Twelve had experienced two or more challenges. The most common challenge experienced before the study began was finding a provider who would be a good cultural, linguistic, or interpersonal fit; see **Figure 2.**

"Two months ago, I went to see my [primary care] doctor. I received a referral, and I had been attempting to contact the psychologist for six weeks. I finally got through to the doctor's office a week and a half ago to make an appointment. And the first available appointment they have is about two months away." Howard, white, in his 50s, Florida

"It's challenging finding therapists that come from the same cultural background. I know that's almost impossible, but I was hoping that maybe I'd least have an option or two, and I haven't been able to find that." Maxine, Black, in her 40s, Michigan

All but one participant faced at least one challenge in searching for a mental health care provider before the study began.

Figure 2. Number of participants who said, prior to the start of the project, they have faced each of the following challenges when searching for a mental health care provider:

Count	Challenge
7	Difficult to find cultural, linguistic, or interpersonal fit
5	Distant or inconvenient location
5	Difficult or overwhelming to find reliable information
5	Search process is time-consuming
5	Too expensive
4	Providers do not accept my insurance
4	Workable appointments times not available
2	Waiting for referrals or unresponsive or slow doctors or insurers
1	Providers are not qualified to treat the participant's diagnosis
1	Did not respond or no challenge

"There seems to be so many ways of trying to find a mental health care provider that it could be overwhelming at times. And also trying to find someone that you want to talk with, feel comfortable talking with." Ted, Black, in his 50s, Maine

Base: All participants, N=17.

Prior to the start of the study, most participants said challenges in searching for a mental health care provider and delays in getting care had already affected their physical health since they were less motivated to take care of themselves, exercise, or eat healthy. Most said their mental health had been negatively impacted because the search process and delays caused them to feel depressed, worried, angry, or frustrated. About three-quarters of the participants indicated that not being able to find a mental health care provider had affected them at work or school, and had affected relationships with friends or family. About half said their finances had been affected; see **Figure 3.**

"I definitely have increased anxiety over the inability to find a provider. It leaves me feeling defeated and depressed." Nathaniel, white, in his 40s, Florida
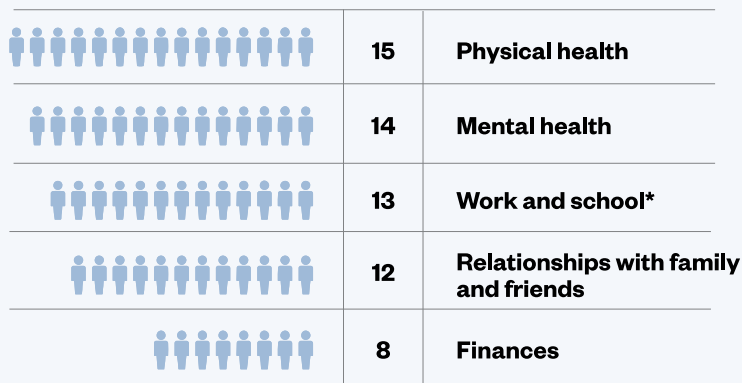
"If I had found a mental health care provider, I believe I would feel better about myself and would take the time to take care of my physical health, whether it be my body as in working out, what I eat, and drinking fewer alcoholic beverages." Eleanor, white, in her 20s, Michigan

"I struggle to get out of bed these days. I've called out sick several times over the course of the past few months just to lay in bed all day and sleep. Procrastination has become more and more a part of my life." Lucia, Hispanic, in her 50s, Florida

> All but one participant reported that searching for a mental health care provider and delays in accessing care had impacted them before the study began.

Figure 3. Number of participants who said delays in finding care affected them in the following ways:

	Count	Category
👤👤👤👤👤👤👤👤👤👤👤👤👤👤👤	15	**Physical health**
👤👤👤👤👤👤👤👤👤👤👤👤👤👤	14	**Mental health**
👤👤👤👤👤👤👤👤👤👤👤👤👤	13	**Work and school***
👤👤👤👤👤👤👤👤👤👤👤👤	12	**Relationships with family and friends**
👤👤👤👤👤👤👤👤	8	**Finances**

*Base: Participants who were employed or in school, n=15

Despite fifteen participants saying that the process of searching for mental health care providers had already been difficult, about half were confident they would find the right provider for them during the study. Among those who were not confident, most said there were just not enough providers available near them, with some specifying there were not enough in-network providers near them. Others were not confident they would be able to find a cultural, linguistic, or interpersonal fit. A few were concerned they would not find affordable care, whether in network or not. One specifically spoke of not being able to even afford copays to see an in-network provider.

> *"I'm not at all confident that I'm going to find the right one. I know that I don't have enough providers to choose from with my insurance company."* Dee, Hispanic, in her 60s, Georgia

> *"I still have a lot of concerns because, again, my issue is not basically about finding a mental health provider, it is that I just can't afford to pay for a mental health provider."* Jaime, Black, in his 50s, Georgia

The three-week search for an in-network mental health care provider

For three weeks, participants were asked to document their experiences searching for mental health care providers. At the end of the three weeks, six participants were able to schedule appointments. But none managed to schedule an appointment with an in-network provider that took place during the study. Five of those who made appointments with their desired type of provider. One who had been looking for a psychiatrist scheduled with a psychologist.

Among the six who scheduled appointments:

Three scheduled in the first week

Three scheduled in the third week

Most participants spent less than three hours each week searching for a mental health care provider; see **Figure 4**. In fact, across all three weeks, nine participants said they spent as much or less time searching than they did during the previous weeks. Some found themselves waiting weeks for insurers or prospective mental health care providers to respond to questions, to get referrals from primary care doctors, or for scheduled appointments to take place. Others said that their time spent searching decreased because they were prioritizing other aspects of their lives.

The challenges of searching and delays in getting care may also have impacted participants' ability to search for a mental health care provider. As discussed later, the search process itself felt overwhelming, which made it difficult to feel motivated to keep searching.

> *"I have had debilitating anxiety this week because I am overwhelmed by how many more hoops I have to jump through to get help. I don't have the extra time or money to start all over again and look even harder for a mental health provider. I can't concentrate. I have so many responsibilities. I am avoiding and I just want to give up."* Sharon, white, in her 40s, Alabama

Six participants scheduled appointments with mental health care providers. Of those:

Two participants were able to have appointments during the study.

One of them knew the provider was out of network but scheduled anyway and negotiated a fee she felt comfortable paying.

The other thought the provider would be in network, but upon going to the appointment found out his insurance was not accepted. However, he felt the fee he ended up paying was affordable.

One participant scheduled an appointment, but had to cancel because the provider did not accept her insurance and she could not afford to pay out of pocket.

Three participants scheduled appointments that would take place after the study period.

Two of them believed the   provider would be in network.

The other was not sure whether or not they would be in network or not.

"Insurance does NOT cover the therapist I am interested in seeing. I have to pay out of pocket for the appointment. I had some financial difficulties this week and had to cancel because I couldn't afford to go." Maxine, Black, in her 40s, Michigan

Most participants spent less than three hours searching for a mental health care provider each week.

Figure 4. Hours spent searching for a mental health care provider, by week:

	Week 1		Week 2		Week 3	
	Less than 3 hours	**3 or more hours**	**Less than 3 hours**	**3 or more hours**	**Less than 3 hours**	**3 or more hours**
Participants	11	6	10	4	11	0

Base: Participants searching for a provider week one, N=17; Participants who were unable to schedule an appointment and continued searching in week two, n=14; Participants who were unable to schedule an appointment and continued searching for a provider week three, n=11.

Searching for mental health care providers required participants to piece together information across a variety of sources and speak to multiple providers.

Across the three weeks of the study, the search for a mental health care provider was nonlinear and repetitive. Participants often had to repeat steps within and across the three weeks of the study, including trying to find information about and contact prospective mental health care providers as well as trying to understand their insurance coverage. Some had to obtain referrals from primary care physicians.

However, not all participants completed every step. For example, nine participants contacted prospective providers at some point during the study. Six inquired about obtaining a referral from their primary care providers. Three tried to understand what their insurance would cover.

Across the three weeks, regardless of whether they scheduled, participants used an average of two different types of sources to identify prospective mental health care providers, confirm whether they were in network, and find additional information to help them gauge potential fit. The most common sources that participants used to identify prospective providers were online searches, insurers, and recommendations from friends and family; see **Figure 5.**

When identifying prospective mental health care providers, participants favored online searches and consulting their insurers.

Figure 5. Number of participants who said they used any of the following sources to identify mental health care providers:

👤👤👤👤👤👤👤👤👤👤	10	**Online search**
👤👤👤👤👤👤👤👤👤	9	**Insurer**
👤👤👤👤👤👤👤👤	8	**Friends and family**
👤👤👤👤👤👤	6	**Primary care doctor**
👤👤👤	3	**Other**
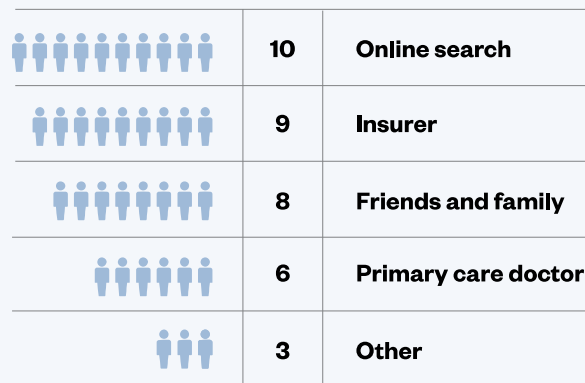
Base: All participants, N=17.

Among the nine participants who contacted prospective providers, most inquired about the next available appointment or whether the provider was in network. Fewer inquired about out-of-pocket costs or tried to determine if the prospective provider would be a good cultural, linguistic, or interpersonal fit.

The process of obtaining a referral from a primary care physician seemed relatively straightforward for three of those who had to do it. But three found it challenging. Two of them were unable to schedule an in-person appointment with their primary care provider within a month to get a referral. One did not have a primary care provider and ended up having to shift from searching for a mental health care provider to searching for a primary care provider. However, she was able to find a one and get a referral in a week.

"Here are the steps I had to take this week: Contact primary care provider's 800 number asking for a referral. Wait on hold for 25 minutes. Operator then stated that I should find a mental health provider from my insurance website and call back and provide the contact info. Found a potential provider but they would not make an appointment without a faxed referral from primary care provider. And no, an email would not suffice. Called 800 number for primary care provider – they do not provide local office number – and requested a faxed referral for doctor I found. Was told I have to go to the primary care provider's office to get the referral. The next available appointment to see primary care provider was 40 days in the future!" Howard, white, in his 50s, Florida

Participants faced an average of three different challenges during their search for a mental health care provider. The most commonly cited challenges were a lack of in-network providers and a lack of appointments available at workable times.

All participants faced at least one challenge in their search for a mental health care provider. In most cases, participants faced different challenges from week to week. The most common difficulties were finding in-network providers and finding providers who had workable appointment times available. Five reported that providers were too far away or in inconvenient locations. Others found the search itself time-consuming and had difficulties fitting it into their already busy schedule, while some expressed frustration around providers, insurers or the referral process holding up the search; see **Figure 6.**

"For me, the most frustrating part about trying to find a mental health care provider has been the limited network through my insurance. I don't want to have to go too far. I want someone that has a good review, so I feel like they would be a good fit. There's just not a lot of options within my network." Nathaniel, white, in his 40s, Florida

Tradeoffs for those who scheduled

Six of the seventeen participants were able to schedule an appointment with a mental health care provider during the study. But scheduling involved tradeoffs. Of the six who scheduled:

Four either know the doctor will not accept their insurance or are unsure if their insurance will be accepted.

Three will wait eight days to four weeks for their appointment, which they believe is too long.

One will have to travel over 90 minutes.

"The problem I ran into was a lot of them are backed up. They got so many patients and they had like two or three month wait times." Misty, white, in her 40s, California

"Just trying to find the time to do this, you know. I've been kind of bombarded with work and I've had some family things happen this week and I just wanna get this going and find the right doctor for me." Georgina, white, in her 50s, state of residence not disclosed

"It's extremely time-consuming, almost feels like it's made intentionally difficult. The biggest frustration is with my primary care physician. Incredibly difficult. Then the providers that are listed through my insurance company aren't easily accessible. Doctors' offices that don't answer the phone. Or if you do get through to them, [they are] making appointments three to four months out, which is just unheard of at least to me in my 57 years of life. Those are the primary difficulties, just getting people to do their jobs from each office, primary care to the specialist and then the insurance company." Howard, white, in his 50s, Florida

Participants cited challenges finding in-network providers, finding providers with workable appointments times, and said the search process itself was complex and time-consuming.

Figure 6. Number of participants who experienced one of the following challenges at least once in three weeks of trying to find a mental health care provider:

Icons	Count	Challenge
👤👤👤👤👤👤👤👤👤	9	Providers do not accept my insurance
👤👤👤👤👤👤👤👤👤	9	Workable appointments times not available
👤👤👤👤👤👤👤	7	Search process is time-consuming
👤👤👤👤👤👤	6	Waiting for referrals or unresponsive or slow doctors or insurers
👤👤👤👤👤	5	Difficult to find a cultural, linguistic, or interpersonal fit
👤👤👤👤👤	5	Distant or inconvenient location
👤👤👤👤👤	5	Too expensive
👤👤👤	3	Difficult or overwhelming to find reliable information
👤👤	2	Providers are not qualified to treat the participant's diagnosis

Base: All participants, N=17.
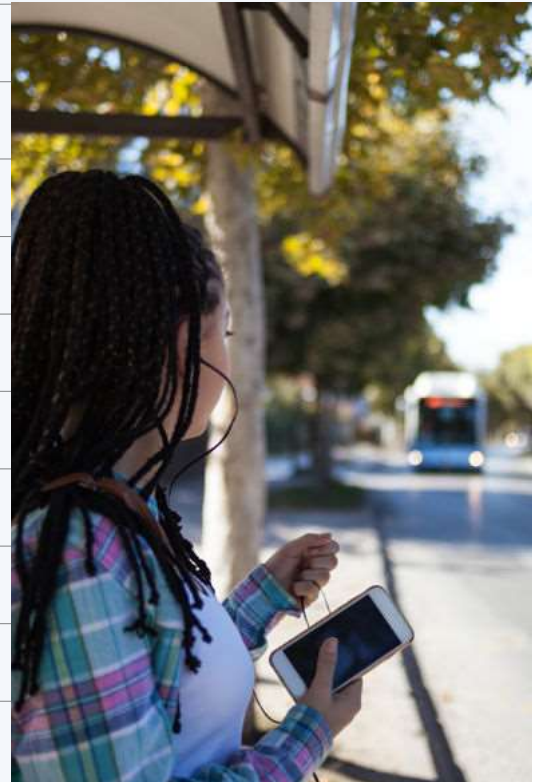
Ten participants experienced "chronic challenges," i.e., the same challenge two or more weeks in a row. Eight of the eleven participants who were unable to schedule an appointment faced at least one challenge chronically, including four who encountered two or more challenges chronically. By comparison, only two of the six participants who made appointments experienced a chronic challenge.

Distant or inconvenient location was a common chronic challenge for those who were unable to schedule. Other chronic challenges encountered by those who were unable to schedule included difficulty finding providers who were in network; waiting for referrals or unresponsive doctors or insurers; difficulty finding providers who were a good cultural, linguistic, or interpersonal fit; or difficulty finding providers who had workable appointment times available.

"So far the major frustration for me would be trying to find a woman doctor that's within my network. There's not that many around my area, which is annoying. I might actually have to go with a male doctor, but I still trying to get a female doctor." Georgina, white, in her 50s, state of residence not disclosed

"What's been most difficult for me is finding a provider, a health care provider that's in network and close by. My options are quite limited." Nathaniel, white, in his 40s, Florida

"The most frustrating thing about trying to find a mental health provider is that you even need a referral in the first place. It just seems to take so much longer that way. First to find the primary care physician, then you have to explain to them what's going on. And of course they can't help you. So you have to do all that stuff and pay all that money, and then you have to go to the next guy for him to maybe say he can help you or not." Sharon, white, in her 40s, Alabama

Tradeoffs for those who experienced chronic challenges

Two of the six participants who were able to schedule appointments experienced at least one chronic challenge and made tradeoffs in response.

Howard, white, in his 50s, Florida

Chronic challenges: Waiting for referrals or for unresponsive or slow doctors or insurers; providers do not accept insurance.

Tradeoff: Scheduled with a provider in network but had to wait what he felt was too long for the appointment. Felt limited by his in-network options and unsure if the provider would be a good interpersonal fit.

"I don't really have a feel for this doctor one way or another. Not much info available in the insurance company app. There aren't many choices available through my insurance. I'd say my main concern is the complete lack of transparency into the doctor's ability as rated by previous patients and status through the insurance company portal."

Jaime, Black, in his 50s, Georgia

Chronic challenge: Providers do not accept his insurance.

Tradeoff: Scheduled with a provider who might be out of network.

"I'm not sure if I found a good one. My main concern is whether they're taking my insurance, but right now this is the best lead I've had."

Participants want better ways to identify in-network providers that are right for them.

Many participants saw the process of searching for mental health care providers as complex, overwhelming, time-consuming, and, in some cases, fruitless. Despite having access to their insurer's directories, they expressed a need for centralized, easy to find, accurate information that would identify in-network providers; list providers' mental health specialties, hospital affiliations if any; and provide additional resources for those seeking help.

"I'd like to be able to see on the website the list of doctors, insurance accepted, their credentials, what they deal with. Websites don't really say anything. It's just pretty vague. So you have to call around find out information, and it takes a while." Georgina, white, in her 50s, state of residence not disclosed

"I feel insurance companies could have more user-friendly websites with lists of doctors in the area who take your insurance." Eleanor, white, in her 20s, Michigan

Participants questioned whether referrals should be necessary for mental health care.

Some participants suggested that referrals should not be required for mental health care because obtaining them prolongs the search process, creates stress, and necessitates scheduling and waiting for expensive primary care appointments.

"A big hang-up is having to go to the doctor, get the referral, wait for the insurance to okay it, wait for the mental health place to have an opening. It's just too long of a process and it should be a shorter, streamlined type of process. I hope that policymakers in Washington, that they will consider a different way that we could get mental health." Lucia, Hispanic, in her 50s, Florida

To make mental health care more accessible, participants wanted it to be more affordable.

Participants spoke of the need to make mental health care more affordable. They experienced two types of financial burdens: Because some said that there were not enough options for in-network providers, some had to turn to out-of-network care, which was more expensive. But even in-network care involved costly copays and other expenses. Therefore, many expressed a need for insurance networks to include more mental health care providers or at least offer some coverage for out-of-network care. Some spoke of the need for mental health care coverage to be as robust as physical health care coverage and for mental health cost-sharing to be no more expensive than physical health cost-sharing. Some believed that mental health care should be available without any cost-sharing at all.

"I think that all copays should be waived for mental health services, I think networks of providers should be larger." Nathaniel, white, in his 40s, Florida

> *"I think there should be more choices of providers that also are culturally sensitive. I live in a place where there's many, many different cultures, and some of the providers that we receive clearly have not had cultural sensitivity training. And when you're talking about your mental health, it's really important to have someone that you can feel safe with and vulnerable with. And I was not willing to do that with the choices that I was given. And so it leads me back to now having to pay out of pocket."* Maxine, Black, in her 40s, Michigan

Searching for a mental health care provider and delays in getting care negatively affected all participants, impacting mental health, physical health, relationships, work, and finances.

All participants were negatively impacted by the process of searching for mental health care providers and by delays in finding providers. Even the six participants who scheduled appointments experienced negative impacts. Sometimes participants were clear about whether it was the search process itself that impacted them or whether they were impacted by not receiving proper mental health care. But often participants experienced the negative impacts of the search process and delays in care as inseparable.

Most participants said their day-to-day lives had been impacted because the complex, time-consuming search process ate up hours they could have used for other responsibilities, exercising, or relaxing. Others said searching for a provider and delays in care made them feel lethargic and lacking in energy to do basic tasks or created a general feeling that the days just drag on.

Five participants said that the search and delays in getting care affected them across all five of the categories that were asked about in this study: mental health, physical health, relationships with friends and family, work and school, and finances. Some indicated that the negative impacts got worse as the weeks passed; see **Figure 7.**

> *"I spend so much time in my bed sleeping, being unmotivated, and taking a lot longer to complete tasks than I used to."* Sharon, white, in her 40s, Alabama

> *"I've spent far too much time attempting to find health care. I could have been taking care of some projects around the house or outside of the house."* Howard, white, in his 50s, Florida

> *"My day-to-day life – it seems to me to just drag on because I'm not able to find the provider that I need, so it makes my days longer and rougher."* Vince, Black, in his 50s, Alabama

Challenges of the search process and delays in finding a mental health care provider negatively impacted all respondent. For most, the impacts got progressively worse.

Figure 7. Number of participants who said delays in finding care affected them in the following ways:

🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍	16	**Mental health**
🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍	16	**Relationships with family and friends**
🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍	15	**Work and school***
🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍🧍	14	**Physical health**
🧍🧍🧍🧍🧍🧍🧍	7	**Finances**

Five participants: impacted in all five categories

Nine participants: impacted in four categories

One participant: impacted in three categories

Two participants: impacted in two categories

Base: All participants, N=17

*Base: Participants who were employed or in school, n=15

Sixteen of the participants indicated that their mental health was affected by the search process and delays in finding a mental health care provider, with some indicating their mental health was affected progressively more each week of the study. Participants said that their mental health symptoms were exacerbated while trying to find a mental health provider. They cited feelings of depression, anxiety, and overall sadness due to delays in getting care.

> *"This process has definitely been frustrating and has caused much anxiety trying to find the right mental health care professional."* Eleanor, white, in her 20s, Michigan

> *"My mental health fluctuates a lot these days. I would like to say without a doubt that I will be okay waiting, but the truth is I'm not sure. Yesterday I had a great day and out of the blue I spent the evening crying and having what felt like the biggest panic attack I've had thus far."* Maxine, Black, in her 40s, Michigan

> **Week one:** *"This week my anxiety has been really hard to deal with. I lack motivation to do just about anything."*
>
> **Week two:** *"I'm definitely more depressed this week than the previous weeks. My motivation is at such a low, I barely feel like I can do anything."*
>
> Nathaniel, white, in his 40s, Florida

Most participants also reported negative impacts on their relationships with family and friends due to challenges and delays in finding a provider. Many reported isolation from social activities. Some said their time was diverted from their family and friends because they had to spend time looking for a mental health care provider. Others pointed to mental health symptoms that strained relationships.

> *"I have definitely been a bit more antisocial because I just feel so tired and putting in the effort to see people is a bit too much right now."* Vicky, white, in her 30s, Texas

> *"I don't want to be around my family and friends because I know that that I'm depressed. I know that I'm kind of sad, and I don't want to be around people like that because I don't want them to feel the same way I do. So I make up excuses why I don't want to be around them."* Jaime, Black, in his 50s, Georgia

> *"The fights between my boyfriend and I have gotten more explosive. I am more defensive and he is exceedingly frustrated with the whole situation. My few friends have all but disappeared due to my isolation and inconsistent follow through with plans."* Sharon, white, in her 40s, Alabama

Many also found challenges in searching and delays in accessing care affected their concentration or productivity at work or school. Some cited physical symptoms such as fatigue or fogginess, while others explained that trying to search for or contact prospective providers during their working hours was impractical. While most described these impacts as annoyances, some actually lost their jobs or missed out on income.

> *"To do my work has always been a challenge just based on the type of work that I do. When you deal with fogginess and unclarity of mental health and sometimes you just want to ball up in a corner and do nothing, it can be very challenging."* Vince, Black, in his 50s, Alabama

> *"This week alone I missed out on $686 of income because I did not complete the job in time, or actually even start it. When I don't complete a job, I have no income. I had no money coming in this week because I was too depressed, too tired, and too lethargic to get out of bed to finish my job. When I was working, I can't stay focused and will get lost in a million different tasks or doing things that have nothing to do with work whatsoever. So because of my unmanaged mental health, I'm missing out on easily $2,000 a month."* Sharon, white, in her 40s, Alabama

> "What affects me most is brain fog. That is what got me fired from my last job in September. And yes, I have been struggling financially from that point on. I'm concerned that when I go back to work, whenever that might be, that I may also not be able to function properly."
> Bonnie, Hispanic, in her 50s, Texas

Most participants also indicated that their physical health was affected by the search process and delays in finding a mental health care provider. Some participants reported headaches. Others indicated that untreated mental health symptoms such as anxiety and depression, made it difficult to maintain their diet and exercise routines, sometimes leading to weight gain and causing greater feelings of anxiety or depression.

> "My lethargy and depression seem worse and worse. I find it nearly impossible to get myself together to exercise. I am taking old blood pressure meds because I have run out and I took my blood pressure tonight and it's the worst reading I've had in a long time. Physically, my health is not well. I'm not eating very well and have gained weight, which makes me even more depressed." Nathaniel, white, in his 40s, Florida

> "This past week my physical health has been worse as well due to not having a mental health provider. My arthritis is worse than normal and my back was hurting so badly that it made it so I could barely get up in the morning and move around. These types of pains and aches typically come on when I'm overly stressed, overworked, or overtired, which is obviously due to the anxiety and depression that I'm going through since I don't have a mental health provider." Sharon, white, in her 40s, Alabama

Conversely, one participant reported that his physical health got better when he was able to book an appointment with a mental health care provider. He specifically stated that because he had an upcoming appointment, he felt motivated to improve his physical health.

> "Knowing that I had the upcoming appointments, I made it to the gym today and worked out. It made a great difference in my physical well-being and mood." Ted, Black, in his 50s, Maine

Seven participants indicated that challenges in searching and delays in accessing care affected them financially. Most who were impacted financially said they made impulsive purchases to help them feel better. Some of were unable to complete their work. Some indicated the need to ration medication that they could not afford.

> *"I did more therapeutic spending this week. I had been cash poor for several weeks due to bills and that was very stressful. I may have spent more to take my mind of my troubles."* Ted, Black, in his 50s, Maine

> *"I have been eating out a lot, which is getting EXPENSIVE. I love cooking and eating what I cook, but nothing sounds good and I don't have the energy to shop."* Vicky, white, in her 30s, Texas

Other participants felt they were in the calm before the financial storm. While they searched for a provider, they were not financially impacted. But many were bracing for the high costs of care once they found a mental health care provider.

> *"Well, obviously since I haven't found a mental health care provider, I haven't had to spend the money on having one. But I'm bracing for that slap in the wallet as soon as I am able to find a health care provider."* Vince, Black, in his 50s, Alabama

Among those who were unable to schedule appointments, few were confident they would find the right provider for them.

Only two of the eleven who were unable to schedule were confident that they would find a mental health care provider who would be a good fit for them.

The other nine were concerned about finding providers who were affordable, in convenient locations, had workable appointment times, or who would be good fits culturally, linguistically, or interpersonally.

> *"I'm not very confident at finding a mental health care provider because of cost and lack of resources in the city that I'm in. I don't believe that the state that I'm in cares anything about mental health."* Vince, Black, in his 50s, Alabama

Methodology

This report summarizes findings from a diary study conducted October 11 to November 14, 2022, with seventeen adult Americans, 18 years and older, whose health insurance was purchased from a state or federal health insurance marketplace.[4] At the start of the project, all participants were trying to find a mental health professional for feelings such as mild or moderate depression, sadness, anxiety, stress, or grief. Participants were financially compensated for their time. Heartland Institutional Review Board reviewed and approved the diary study.

The first week of the diary study, participants were asked questions about the type of mental health care provider they were searching for and about their previous experiences trying to find a mental health care provider. The following three weeks of the diary study, participants were asked to document the steps they took to search for a mental health care provider and the challenges they encountered along the way. If they were able to schedule an appointment, they were asked about the appointment. Participants were also asked to reflect on how, if at all, delays in finding a mental health care provider or delays in seeing a mental health care provider had affected them across their lives, including financially, day to day, at work or school, in their relationships with friends or family, and their mental and physical health. During the last week of the project, participants were also asked about their views on the health care system and how they believe it can be improved.

The diary study protocol was developed by Public Agenda and included a mix of structured open-ended questions and multiple-choice questions. The diary study used a web-based platform called QualBoard. Participants logged in weekly to document their responses. Sago, previously known as Schlesinger Group, recruited the diary study participants to Public Agenda's specifications and managed technical aspects of QualBoard. While a few questions required participants to respond via video, for most questions participants had the option to respond via text or video. All video responses were transcribed by a professional transcriber, Kelsey Transcripts.

By identifying commonalities between participants' responses, Public Agenda coded qualitative responses into quantifiable data to track responses across the study. Although qualitative responses were quantified, the data only represents what participants explicitly mentioned in response to open-ended questions and may not be representative of everything they did or experienced. For example, while three participants specifically indicated that they tried to understand their insurance coverage, others may have done so but did not specifically mention it in response to this question:

What, if anything, have you done over the last seven days to try to find a mental health care provider? Think about all the different things that you may have ever done over the last seven days, such as:

- Trying to find out which mental health care provider takes your insurance
- Trying to schedule appointments
- Calling your insurance company or using your insurance company's website
- Searching online for providers
- Asking your primary care provider for a referral
- Getting recommendations from family or friends
- Anything else you might have done to try to find a mental health care provider

To inform the development of the diary study, Public Agenda designed and conducted three demographically diverse online focus groups in May 2022 with people who in the past two years have wanted or needed counseling or therapy

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[4] Twenty participants were recruited to complete the diary study. Three participants completed only 36 percent or fewer of the diary study questions and were therefore removed from the analysis.

from a mental health professional. All focus group participants had also tried to make an appointment with a mental health professional within two years or less before the focus groups. Fieldwork National Recruiting Center recruited participants for two of the focus groups and Sago recruited participants for one of the focus groups. All focus group participants were recruited to Public Agenda's specifications. Participants were financially compensated for their time. Focus group video responses were transcribed by a professional transcriber, Kelsey Transcripts. The focus group portion of this study was not reviewed by Heartland Institutional Review Board.

For more information about this study, go to **https://www.publicagenda.org/reports/netad-2023/** or contact **research@publicagenda.org**.

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Sample characteristics

Gender

Male	6	
Female	11	

Age

20-29	1	
30-39	2	
40-49	5	
50-59	8	
60-64	1	

Race/ethnicity

Black or African-American	7	
Hispanic or Latino	3	
White	7	
Multiracial	0	

Income

Under $50,000	6	
$50,000 to under $100,000	8	
$100,000 or more	3	

Education

High school/GED or less	0	
Some college/2-year degree/trade school degree	6	
4-year college degree or more	11	

Location

Northeast	2	
Southeast	9	
Midwest	2	
Southwest	2	
West	1	
Not specified	1	