Nowhere to Turn

Findings from a survey on access to mental health and addiction treatment among Missouri health plan beneficiaries
**Mission:** The Missouri Federation of Behavioral Advocates works to ensure consumers have a voice in the development and implementation of behavioral health policy.

**Federation Members:**
- Adapt of Missouri
- Catholic Charities of Greater St. Louis
- Compass Health Network, Independence Center
- Maplewood Residential Center
- Mental Health America of Eastern Missouri
- Mental Health America of the Heartland
- Missouri Coalition for Community Behavioral Healthcare
- Missouri Recovery Network
- NAMI Jefferson City, NAMI Kansas City
- NAMI Missouri
- NAMI St. Louis
- NAMI Southwest Missouri
- Places for People
- ... and many individual advocates.

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Introduction

In the face of rising suicides and opioid deaths, mental health and substance use treatment is more urgently needed than ever. In 2016, Missouri lost 1,133\textsuperscript{1} people to suicide. At 1,317\textsuperscript{2} deaths, lethal drug overdoses were at an all-time high. Combined, there were over two and a half (259\%) more suicides and overdose deaths than traffic fatalities.\textsuperscript{3}

Professional help will save and restore lives. Yet even people with health insurance are hard pressed to access mental health and addiction treatment when they need it.

A major factor is the inadequacy of health plan provider networks for behavioral health. A recent national study by the Milliman group\textsuperscript{4} examined two large databases of administrative claims data covering 42 million lives. Missouri data for 2015 show that 14.6\% of behavioral health visits were with out of network providers compared to 2.9\% for primary care and 4.2\% for medical specialty.

Several factors could contribute to this disparity, although the same study found marked differences in reimbursement rates between primary care and behavioral health - for the type of same service. Data from 2015 for evaluation and management visits revealed that reimbursement for primary care providers averaged 104.3\% of the allowable Medicare rate while behavioral health providers only received 78.5\% of the Medicare rate. Given low reimbursement rates, management practices and formulary design, behavioral health providers increasingly opt out of health plan networks altogether.

A series of studies from the National Alliance on Mental Illness (NAMI)\textsuperscript{5} found that health plan members are often forced to seek out of network behavioral health providers and pay steep out of pocket costs over and above monthly premiums. Confronted with these obstacles, it is not uncommon for consumers to delay needed care or forgo it altogether, leading to problems at home, at school or on the job. When people reach a breaking point, families fracture and individuals may find themselves isolated, in legal trouble, in debt and with no place to live.

Lack of access to behavioral health care also lays a heavy burden on families. A National Alliance for Caregiving study\textsuperscript{6} found that caregivers spent an average of 32 hours per week for 9 years on end caring for an adult relative with mental illness. The strain leads to isolation, poor health, employment challenges and financial instability.

Concerned with the harmful and too often fatal consequences of barriers to care, the Missouri Federation for Behavioral Health Advocates conducted an online survey in the winter of 2017-2018. The survey asked about health plan beneficiary experiences with seeking behavioral health treatment.

This study found behavioral health provider networks to be so limited that health plan beneficiaries had difficulty finding in-network help. When an out of network provider was available, beneficiaries encountered greater out of pocket costs, often placing care out of reach. As a result, individuals deferred treatment, stretched the time between appointments or dropped out of care. Others sacrificed necessities such as food and housing to stay in treatment.
**Methodology**

The Missouri Federation for Behavioral Health conducted an online survey to examine what health plan members experience when they seek mental health or substance use care. The survey compared access to mental health and substance use services with other types of medical care.

The study drew a convenience sample of 152 respondents from December 1, 2017 to February 2, 2018. This report is based on the 115 (75.7% of respondents) who met study criteria. The sample excluded seven incomplete surveys and 17 where the person who needed care was uninsured. Another 15 respondents lived out of state although two were included in the sample because the person in care was insured through Missouri-based parents.

Survey respondents could answer for themselves or another person for whom they had reliable information about health coverage. Over half answered for themselves (57%). More than a quarter (26%) responded for a child, mostly for an adult child; only 3% of the persons in care being under 18 years old. Other categories included spouse, domestic partner, parent, sibling or other. The typical person in care was female (54%), Caucasian (82%) and working full or part time (58%). See Appendix A for additional detail.

**Type of Health Insurance**

Respondents were provided with a list of possible types of health coverage (private-individual, private-employer, Medicaid, Medicare, Tricare, VA, student health, other) and asked to indicate which applied to the person in care. Multiple options could be selected.

More than half had private health plans, either through their employer (41%) or private insurance purchased as an individual (11%) including 12% whose coverage was purchased in the health insurance exchange established under the Patient Protection and Affordable Care Act (ACA). Medicaid (MOHealthNet) covered 20% of this sample, while other government sponsored health coverage included Medicare (22%) and Tricare or VA Health Benefits (5%). Two respondents (1%) were in a student health plan.
**Services Utilization**

Respondents were asked what types of services the person used for mental health, substance use treatment and for other medical care. Primary care (28%) was the most common type of service followed by a mental health prescriber (22%) such as psychiatrist or psychiatric nurse practitioner. Mental health therapy (18%) was the next most common service followed by other medical specialty care (16%). Utilization of substance use outpatient care was low (3%). Inpatient or residential care for substance use (1%) was also lower than mental health inpatient (6%) or general hospital care (5%).

![Figure 2: Services Used in the Past Year](image)

**Health Plan Provider Network Access**

Limitations in health plan provider networks prevented people in this study from accessing needed services. Across all specialties, care recipients had difficulty finding in-network providers. For some services, recipients were likely to delay care or opt out of treatment completely because they could not pay the cost even though they had health insurance.

For each type of service used, respondents were asked whether the provider was in the health insurance network. Medical specialty was selected as the comparison to assess parity between behavioral health and other medical care.

**People in this study often had to seek out of network providers for behavioral health care.** Compared to outpatient care for medical specialty treatment (12%), outpatient mental health therapists (33%) and substance use counselors (40%) were three times more likely to be out of network, and psychiatric prescribers (25%) were twice as likely. See figure 3.

**Respondent:** *My primary problem with the mental health aspects of my insurance has been that reimbursement for psychiatrists are so low that I have not been able to find a competent psychiatrist who accepts my insurance. As a result, I have to pay for my appointments 100% out of pocket. This has resulted in my being able to go much less often for psychiatric care.*
Comparison of inpatient and residential care for this study should be interpreted with caution because so few people accessed facility-based services during the past year that even small differences in numbers accentuate variance in percentage. With that disclaimer, only 4% of hospital care for general medical conditions was out of network, compared to 19% for out of network psychiatric hospital care and 29% for residential substance use treatment. Out of network facilities represented half of the residential care for substance use (44%) and all residential care for mental health treatment (100%).

Figure 3: Out of Network Outpatient Care

Figure 4: Out of Network Hospital or Residential Care
Provider Network Barriers

For each type of outpatient service, respondents were asked whether they had tried to access service but were unable to find a provider in their health plan. Provider network barriers were reported to be higher for both mental health therapists (36%) and mental health prescribers (23%) than medical specialists (16%). Substance use counselors were as likely to take insurance as other medical specialists.

Service recipients were three times more likely to go out of network for hospital and residential treatment for mental health or substance use care than for other medical conditions.

Respondent: I needed to access eating disorder treatment. There were zero in-network therapists with this focus, or clinics or residential treatment facilities. The health plan was not proactive in helping me access care and seemed to actively obstruct efforts to make single-case agreements with providers. I ended up paying for therapy and was never able to access intensive care despite the vehement recommendation of my treatment team.
Out of Pocket Costs

For each type of outpatient service, respondents were asked whether the care recipient had attempted to access the type of care but could not afford the out of pocket cost. Respondents were more likely to encounter cost barriers for mental health therapists (30%) and non-mental health medical specialists (23%) than mental health prescribers or substance use counselors (10%).

Comparing inpatient services, slightly more respondents encountered cost barriers for mental health hospital (14%) and residential treatment for substance use (12%) than for general medical hospital services (9%). Again, because the actual number of respondents is small, these figures should be interpreted with caution.

Respondents were asked about copayments, co-insurance and other out of pocket costs for outpatient substance use treatment, mental health, medical specialty and primary care. Out of pocket costs were higher for mental health therapists and prescribers. As shown in figure 9, more respondents paid over $200 per visit for mental health therapists and prescribers than for medical specialty care or substance
use counseling. More respondents paid less than $100 per visit for primary care and medical specialty care than for mental health prescribing or therapy.

More respondents owed over $200 per day for psychiatric hospital treatment than for other types of inpatient care. By contrast, more respondents owed less than $100 per day for medical hospital care. Due to the small number of people in this study who used inpatient care, this analysis examines frequency rather than percentage and should be interpreted with caution.

Annual deductibles also contributed to out of pocket costs for beneficiaries. A deductible is amount in medical bills the member must pay each year before the health plan begins to cover the cost of care.
Nearly a quarter (24%) of study respondents did not know their annual deductible, but those who did reported a wide range from $0 for Medicaid to over $10,000 per year for private individual plans.

**Figure 11: Annual Deductible**

<table>
<thead>
<tr>
<th>Deductible Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No deductible</td>
<td>10%</td>
</tr>
<tr>
<td>$1 – 999.99</td>
<td>20%</td>
</tr>
<tr>
<td>$1,000 – 2,499.99</td>
<td>15%</td>
</tr>
<tr>
<td>$2,500 – 4,999.99</td>
<td>15%</td>
</tr>
<tr>
<td>$5,000 – 9,999.99</td>
<td>5%</td>
</tr>
<tr>
<td>$10,000 or more</td>
<td>0%</td>
</tr>
</tbody>
</table>

**Respondent:** *We had to apply for charity care at the hospital to be able to pay part of the deductible. We could not afford to refill her medications at times until deductible was met.*

**Treatment Review**

Health plans use a variety of managed care techniques to ensure quality of care and control costs. This survey examined application of two common tools, prior authorization and medical necessity standards, to mental health care, substance use treatment and medical specialty care.

For some types of care, health plans require providers to request authorization in writing before administering a given course of treatment. Survey respondents were asked whether prior authorization was required for mental health, substance use or medical specialty care. Results, as shown in the figure below, show no disparity between medical specialty (25%) and mental health care (26%), but 75% of the respondents seeking substance use care reported prior authorization as a requirement. These results should be viewed with caution given how few people in this study sought substance use care.

**Figure 12: Prior authorization required**

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health</td>
<td>20%</td>
</tr>
<tr>
<td>Substance Use</td>
<td>80%</td>
</tr>
<tr>
<td>Medical Specialty</td>
<td>20%</td>
</tr>
</tbody>
</table>
Health plans approve or deny care based on medical necessity, referring to whether the care meets accepted standards of medicine and is needed to prevent, diagnose, or treat a condition. In this study, medical necessity denials were highest for substance use treatment followed by medical specialty care, then mental health care. When respondents in this study were asked whether services recommended by their provider had been denied due to medical necessity in the past year, a third had experienced denials of substance use care (33%), a quarter (26%) had been denied medical specialty care while only 8% had been denied mental health care.

**Figure 13: Services denied - medical necessity**

- Mental health
- Substance use
- Medical specialty

**Access to Medication**

Prescription medication can be a critical part of treatment across domains of care. Respondents were asked how well the health plan covered out of pocket costs for medications. One in six reported full coverage for mental health (17%) and medical specialty (16%) drugs, while only 8% reported full coverage for medications to support substance use treatment.

More health plans partially covered the cost of medications, with health plan members responsible for co-insurance, or a percentage of the cost. In this study, 67% of respondents reported partial coverage for mental health and medical specialty drugs respectively, while 50% reported partial coverage for substance use medications. Medication was least likely to be covered at all for substance use (25%) while 6% reported no prescription coverage for mental health and 3% for other medical specialty care.

**Figure 14: Health plan cover medication costs?**

- Full cost covered
- Part of cost covered
- No cost covered
- Don’t know

Substance Use  | Mental Health  | Medical Specialty
**Medication cost barriers:** Respondents were asked whether the person had been unable to fill a prescription because they could not afford the out of pocket cost. Nearly a quarter (23%) had been unable to fill a prescription for medical specialty care, 19% for mental health and 17% for substance use treatment prescriptions.

**Types of covered medication:** Respondents were asked whether types of covered medications were limited by the health plan. A third (31%) reported no limits for mental health medications, 28% for medical specialty drugs and 25% for medications to assist with substance use treatment. Generic only or generic preferred, and preferred drug lists were the most common limits on prescriptions for mental health (8%) and substance use (8%) treatment while 7% reported those types of limits for other medical specialty drugs. High cost medication was not covered for 5% of respondents seeking medical specialty care, but only 2% for mental health treatment. Pre-authorization was required for 7% of those who needed medication as part of medical specialty care, but only 4% for mental health. No respondents reported these types of limitations for medications to treat substance use.

![Figure 15: Health plan limit on type of medication](chart)

**Respondent:** She was taking [a brand name medication] that was not covered and the out of pocket cost was over $900.00 per month. Since we could not afford this, she was forced to change to a different medication. By March she was unstable and by May was in a manic episode that lasted all summer. She changed medication numerous times and by August was back on the medication via samples provided by the doctor. We are facing the same issue this year and even our agent can't get a direct answer about this medication.
**Annual or Lifetime Limits**

Respondents were asked whether health benefits were subject to annual or lifetime limits in terms of dollars or the number of visits. Most respondents did not know but of those whose did, half (50%) had visit limits for mental health, 25% for medical specialty care, 16% for substance use care and 9% for primary care. Annual or lifetime dollar limits were reported by 35% of those needing mental health care, 29% for medical specialty care, 23% for primary care and 13% for substance use care.

![Chart showing annual or lifetime limits on care](chart16)

**Health Plan Customer Service**

Respondents were asked whether they had contacted the health plan in the past year because they were confused or dissatisfied. Of the 28 respondents who did so, more were concerned about medical specialty care (29%) than mental health (19%) or substance use treatment (17%).

![Chart showing contacted the health plan in the last year](chart17)
As shown in figure 18, health plans were most often contacted for explanation of benefits while the next most common reasons were for help finding a provider or to appeal denial of care.

**Figure 18: Reasons for contacting the health plan**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Substance use</th>
<th>Mental health</th>
<th>Medical Specialty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefit explanation</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Help finding a provider</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Needed additional care</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Appeal denial of care</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Cost sharing</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Billing error</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**Discussion**

Individuals and employers who purchase health insurance expect access to care, yet coverage for mental health and substance use treatment continues to be inadequate despite the passage of federal parity laws. Stronger regulatory oversight is needed to enforce existing state mental health and addiction parity laws. Additionally, the state should pass legislation or issue regulations requiring health plans to submit regular reports demonstrating equivalent access to behavioral health and medical/surgical care.

Limited provider networks for mental health and substance use treatment either prevented people in this study from getting needed care or compromised the frequency or quality of treatment. For some who were forced to access out of network providers, cost increases presented a hard set of choices: defer care, stretch the time between appointments, drop out of care or sacrifice necessities to pay for treatment. Families contributed financially, in some cases, at considerable hardship to themselves.

Access to prescribed medication was problematic for some respondents. Psychiatric prescribing often requires multiple type and dosage trials to achieve an effective regimen. Inadequate formularies, onerous prior authorization procedures and high out of pocket costs can upset this delicate balance. Although people in this study were as likely to experience pharmacy limitations for medical specialty prescriptions as for mental health, any disruption in psychiatric care can trigger a crisis. Recovery can take years, requiring costly intensive care and seriously compromising the life course of an individual.

**Respondent:** *I feel like we pay an excessive amount for insurance that covers little to nothing. As our options dwindle, we must now buy off the exchange. Doctors she has seen for years are no longer in network. It is not okay to mess with people's mental health.*
**Policy Recommendations:**

**For the state:**

The state should enact Missouri insurance parity laws aligned with the Mental Health Parity and Addiction Equity Act. The law should oblige state regulators to ensure parity between behavioral health and physical health by requiring health plans to demonstrate compliance with parity law and by conducting regular market audits of health plans doing business in the state.

The state should strengthen and expand the behavioral health workforce through collaborative programs with colleges and universities, and scholarships, fellowships and educational loan forgiveness programs, in return for a period of service with an underserved population. These programs should emphasize recruitment of applicants from rural communities and other underserved populations.

The state should establish a program to reimburse psychiatric and addiction treatment experts for consultation with primary care providers.

The state should require mental health screening at every physical exam throughout the lifespan. The state, health plans and managed care organizations should facilitate robust consultation and referral protocols for instances when concerns arise from screening.

**For health insurance plans and manage care organizations:**

Health plans should strengthen the existing workforce by increasing reimbursement rates for behavioral health prescribers, therapists and counselors, as well as inpatient and residential treatment facilities.

Health plans should stretch the prescriber workforce by utilizing advanced practice psychiatric nurses and other clinicians with appropriate training to prescribe psychiatric medications.

Health plans should increase reimbursement for and reduce barriers to telehealth delivery of mental health and addiction services.

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**Respondent: Drug addiction help for everyone should be covered as a disease. It’s sad that you can only get help if you can afford $10,000 a month for treatment or live on the streets. Those of us in between can’t get treatment. There is no one number for first time families, a place we can call to see who takes our insurance. I spent countless hours calling places to hear “No we don't take your insurance.” When you need something right away and your family member goes in for treatment, then is denied help, it feels like you are riding a stationary bike getting nowhere.**
Appendix A: Care Recipient Characteristics

Survey responses could represent the respondent or another person for whom the respondent could provide reliable data. A majority of people responded for themselves (57%) or their child (26%). However, since only 3% of the responses were for people age 0 – 18, most parents were responding for an adult child. A total of 18% responded for a spouse, domestic partner, parent, sibling or other. Typical care recipients were female (54%), Caucasian (82%) and working full or part time (58%).
References


ii National Center for Health Statistics; Number and age-adjusted rates of drug overdose deaths by state, US 2016. Centers for Disease Control and Prevention, CDC: https://www.cdc.gov/drugoverdose/data/statedeaths.html


