BEHAVIORAL HEALTH

Research on Health Care Costs of Untreated Conditions is Limited
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What GAO Found

According to 2017 survey data from the Substance Abuse and Mental Health Services Administration (SAMHSA), an estimated 56.8 million adults had a behavioral health condition—that is, a substance use or mental health condition. An estimated 39.7 million of these individuals did not receive treatment for their behavioral health condition in the past year, with more than 80 percent not perceiving a need for treatment. The survey also indicates the reasons why individuals who perceived a need for treatment did not receive it, including cost, stigma, and access challenges, such as not knowing where to go for treatment.

Figure: Estimated Number of Adults with Untreated Behavioral Health Conditions, 2017

In 2017, of the 56.8 million adults aged 18 or older with a behavioral health condition...

...about 39.7 million (70 percent) did not receive treatment in the past year

18.7 million with substance use conditions, 17.2 million of those are untreated
11.2 million with serious mental illness, 3.7 million of those are untreated
35.4 million with other mental illness, 22.9 million of those are untreated

The numbers on the right side add up to more than the numbers on the left side due to co-occurring substance use conditions and mental illness.

Not treating behavioral health conditions can lead to other health care costs, such as the costs of emergency care for an overdose. However, GAO found that research on such costs is limited and there is no generally accepted estimate of all the health care costs associated with untreated behavioral health conditions. According to experts GAO met with, available research in this area is limited by methodological challenges, including determining which health care costs can be attributed to an untreated behavioral condition, and by limited data on the full prevalence of certain behavioral health conditions. The 29 studies GAO reviewed compared the health care costs associated with treating and not treating certain behavioral health conditions in adults. These studies were limited in scope—focusing, for example, on specific behavioral health conditions and specific geographic areas. Among these 29 studies,

- 20 found higher health care costs associated with untreated adults,
- 6 found that health care costs were lower for untreated adults, and
- 3 reported either mixed results or no observable difference.

Experts and stakeholders cited reasons why untreated behavioral health conditions can be associated with higher health care costs. For example, adults with untreated behavioral conditions may have other related, physical health conditions that may not be well managed and have their own costs.
# Contents

<table>
<thead>
<tr>
<th>Letter</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>5</td>
</tr>
<tr>
<td>Survey Data Show Most Adults with Untreated Behavioral Health Conditions Do Not Perceive a Need for Treatment, and Those Who Do Cite Barriers Accessing Care</td>
<td>11</td>
</tr>
<tr>
<td>Available Research Is Limited and Does Not Estimate Overall Health Care Costs Associated with Untreated Behavioral Health Conditions</td>
<td>19</td>
</tr>
<tr>
<td>Agency Comments</td>
<td>29</td>
</tr>
<tr>
<td>Appendix I</td>
<td>Objectives, Scope, and Methodology</td>
</tr>
<tr>
<td>Appendix II</td>
<td>Bibliography</td>
</tr>
<tr>
<td>Appendix III</td>
<td>Participants in GAO's Meeting with Experts on Untreated Behavioral Health Conditions in Adults</td>
</tr>
<tr>
<td>Appendix IV</td>
<td>Other Costs Associated with Untreated Behavioral Health Conditions</td>
</tr>
<tr>
<td>Appendix V</td>
<td>GAO Contact and Staff Acknowledgments</td>
</tr>
</tbody>
</table>

## Table

| Table 1: Participants in GAO's Meeting with Experts on Untreated Behavioral Health Conditions in Adults, June 2018 | 45 |

## Figures

| Figure 1: Estimated Number of Adults with Behavioral Health Conditions, 2017 | 6 |
| Figure 2: Estimated Number of Adults with Untreated Behavioral Health Conditions 2017 | 8 |
Figure 3: Perceived Need for Treatment among Adults Aged 18 or Older with Substance Use or Mental Health Conditions Who Did Not Receive Treatment in Past Year, 2017

Figure 4: Summary of 29 Studies GAO Reviewed on Health Care Costs Associated with Untreated Behavioral Health Conditions

Abbreviations

DSM-IV  Diagnostic and Statistical Manual of Mental Disorders (4th edition)
HHS  Department of Health and Human Services
National Academies  National Academies of Sciences, Engineering, and Medicine
NSDUH  National Survey on Drug Use and Health
SAMHSA  Substance Abuse and Mental Health Services Administration

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February 28, 2019

The Honorable Frank Pallone  
Chairman  
The Honorable Greg Walden  
Republican Leader  
Committee on Energy and Commerce  
House of Representatives

The Honorable Michael C. Burgess  
Republican Leader  
Subcommittee on Health  
Committee on Energy and Commerce  
House of Representatives

The Honorable Joe Kennedy  
House of Representatives

The Honorable Doris Matsui  
House of Representatives

The Honorable Fred Upton  
House of Representatives

Behavioral health conditions—mental health conditions and substance use conditions—affect a substantial number of adults in the United States. National survey data from the Substance Abuse and Mental Health Services Administration (SAMHSA) within the Department of Health and Human Services (HHS) indicate that there were an estimated 56.8 million adults with behavioral health conditions in 2017, about 39.7 million of whom had not received treatment for their condition in the past year.¹ Further, a recent study covering 2008 through 2014 found that less than 10 percent of adults with both mental health and substance use conditions received both mental health care and substance use treatment

¹These data, from SAMHSA’s National Survey on Drug Use and Health for 2017, were the most recent data available at the time of our review. When reporting these data, we define adults with untreated substance use conditions as those who did not receive treatment for substance use at a specialty facility, and we define those with untreated mental health conditions as those who did not receive mental health services.
Adults with untreated behavioral health conditions may require other health care services while—or even because—their behavioral health conditions go untreated. For example, adults with an untreated substance use condition may visit a hospital emergency department to receive care for a drug overdose. Adults with untreated behavioral health conditions may also require treatment, including prolonged hospital stays, for other medical conditions that are exacerbated by an untreated behavioral health condition, which can further increase health care costs. For example, the National Institute of Mental Health reported that people with depression have an increased risk of cardiovascular disease, diabetes, stroke, Alzheimer’s disease, and osteoporosis. Similarly, the Surgeon General has reported that alcohol misuse and illicit drug use can have long-term adverse effects on physical health, such as increasing the risk of cardiovascular and cardiopulmonary diseases, pancreatic disease, and hypertension, among others.

The health care costs for people with behavioral health conditions—both treated and untreated—often accrue to federal and state health care programs such as Medicaid. For example, in 2011, while adult Medicaid enrollees with behavioral health conditions accounted for 27 percent of enrollment, they accounted for 53 percent of spending due to their more intensive health care needs—both physical and behavioral—requiring office visits, inpatient stays, emergency department visits, and prescription drugs. Researchers and policy makers have raised questions about what the overall impact on health care costs would be if treatment for behavioral health conditions were more widely available and there were fewer adults with untreated conditions.

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You asked us to review available information on adults with untreated behavioral health conditions. This report describes

1. reasons why some adults with behavioral health conditions do not receive treatment for their conditions, and
2. what is known about the health care costs associated with untreated behavioral health conditions in adults.

To describe why some adults with behavioral health conditions do not receive treatment for their conditions, we analyzed data from SAMHSA’s National Survey on Drug Use and Health (NSDUH) for 2017. NSDUH collects data through face-to-face interviews with U.S. civilians who are not institutionalized. The survey includes people who live in non-institutional group residences, such as shelters, rooming houses, or dormitories, as well as civilians living on military bases.6 In the survey, respondents are asked about their alcohol and illicit drug use and mental health conditions, as well as any treatment they received in the prior year and the reasons for not receiving treatment for perceived unmet needs. Based on these responses, SAMHSA estimates results for the U.S. population. We also reviewed literature on the reasons why adults do not receive treatment for their behavioral health conditions. For all of the studies we reviewed for both objectives, we reviewed the study methodology and determined that they were sufficiently reliable for our reporting purposes. All estimates we present based on the NSDUH data have margins of error at the 95 percent confidence level of plus or minus 10 percent or less, unless otherwise noted. To assess the reliability of these data, we reviewed relevant documentation and interviewed knowledgeable SAMHSA officials. We determined that the data were sufficiently reliable for our reporting purposes. We also obtained feedback from SAMHSA officials on our presentation of the NSDUH data, including figures and notes.

To describe what is known about the health care costs associated with untreated behavioral health conditions in adults, we conducted literature searches for studies that compared the health care costs for those with

6NSDUH does not include homeless or transient individuals who do not use shelters, military personnel on active duty, or residents of institutional group quarters, such as jails and hospitals. See Substance Abuse and Mental Health Services Administration, Center for Behavioral Health Statistics and Quality, 2017 National Survey on Drug Use and Health: Methodological Summary and Definitions, (Rockville: Md., September 2018) for further information about NSDUH.
untreated behavioral health conditions to those who received treatment for their condition. We identified and analyzed 29 studies, published from 1996 through 2017, that met our selection criteria. (See appendix I for a detailed description of the methodology we used to address both research objectives, including the selection criteria. See appendix II for a bibliography of the 29 studies we analyzed for this report.) For illustrative purposes, we also identified studies related to the costs of behavioral health conditions more broadly. We identified these studies through both our literature searches and through recommendations by experts in a meeting we convened. Our focus was on the health care costs associated with untreated behavioral health conditions, not on other related costs, such as lost employment and productivity.

To address both objectives, we worked with the National Academies of Sciences, Engineering, and Medicine (National Academies) to identify experts in fields associated with estimating the health care costs of behavioral health conditions. The experts’ fields included health economics, substance use, mental health, public health, public policy, and statistics, among others. We convened a two-day meeting of 13 such experts to obtain their views on the reasons adults with behavioral health conditions do not receive treatment for their conditions, the health care costs associated with untreated behavioral health conditions, and possible limitations in the data that may be used to estimate those costs.7

In addition to these experts, we interviewed other stakeholders, including officials from HHS, the Department of Defense, and the Department of Veterans Affairs, and stakeholders from organizations working in areas such as substance use, mental health, and health economic research related to behavioral health.

We conducted this performance audit from October 2017 to February 2019 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

7See app. III for more information on the experts we consulted.
NSDUH data show that of the estimated 56.8 million adults aged 18 and older with behavioral health conditions in 2017, an estimated 10.2 million had a substance use condition only, 38.1 million had a mental health condition only, and 8.5 million had both a substance use and a mental health condition, referred to as co-occurring conditions. Examples of substance use conditions include alcohol use disorders and opioid use disorders. Examples of mental health conditions include depression, anxiety disorders such as phobias, and post-traumatic stress disorder. NSDUH classifies some of the mental health conditions reported in the survey as a serious mental illness.

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8 For the purposes of this report, we use the term “adults with a substance use condition” to refer to those 18 and older that NSDUH classifies as having a “substance use disorder.” Substance use disorder is defined in NSDUH as meeting the criteria for illicit drug or alcohol dependence or abuse based on definitions in the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). Similarly, we use the term “adults with a mental health condition” to refer to those classified by NSDUH “with any mental illness.” NSDUH defines any mental illness as a diagnosable mental, behavioral, or emotional disorder that meets DSM-IV criteria (excluding developmental disorders and substance use disorders). For more information on these criteria, see American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (4th ed.), Washington, D.C., 1994.

9 NSDUH defines a serious mental illness as any diagnosable mental, behavioral, or emotional disorder that results in serious functional impairment. NSDUH defines other mental illness as any mental disorder not classified as serious.
Figure 1: Estimated Number of Adults with Behavioral Health Conditions, 2017

Source: Substance Abuse and Mental Health Services Administration, National Survey on Drug Use and Health, 2017. | GAO-19-274

Note: Adults with a substance use condition are individuals 18 and older classified in the National Survey on Drug Use and Health (NSDUH) as having a “substance use disorder.” Adults with a mental health condition are those individuals 18 and older NSDUH classifies as having “any mental illness.” Adults with co-occurring conditions are those individuals 18 and older NSDUH classifies as having both a substance use disorder and a mental illness.

The 2017 NSDUH data show that an estimated 39.7 million, or 70 percent, of adults with a behavioral health condition did not receive
treatment for their condition in the past year. The percentage of untreated adults varied by specific type of behavioral health condition. Specifically, NSDUH data show that an estimated 92 percent of those with substance use conditions did not receive treatment for their condition, compared with 33 percent of those with a serious mental illness, and 65 percent of those with other mental illness. (See fig. 2.)

10Adults with untreated substance use conditions are adults identified in NSDUH as having a substance use disorder who did not receive treatment in the past year at a specialty facility (i.e., inpatient or outpatient drug and alcohol rehabilitation facility, inpatient hospital, or mental health center) to reduce or stop illicit drug or alcohol use, or for medical problems associated with illicit drug or alcohol use. Some of these adults may have received treatment at a non-specialty facility (emergency room, private doctor’s office, self-help group, or prison or jail). However, we focused our analysis of NSDUH data on treatment at a specialty facility because some key estimates—such as the percentage of adults with untreated substance use conditions who perceived a need for treatment—were available in SAMHSA’s published tables only for the subpopulation who needed but did not receive substance use treatment at a specialty facility. Adults with untreated mental health conditions are adults identified in NSDUH as having a mental illness who did not receive inpatient or outpatient mental health treatment or counseling or prescription medication for problems with emotions, nerves, or mental health in the past year. Adults with untreated co-occurring conditions are adults identified in NSDUH as having both a substance use disorder and a mental illness who did not receive one or both of the above described treatments in the past year (i.e., those who were untreated for at least one of their conditions).
Figure 2: Estimated Number of Adults with Untreated Behavioral Health Conditions 2017

In 2017, of the 56.8 million adults aged 18 or older with a behavioral health condition...

- 18.7 million with substance use conditions, 17.2 million of those are untreated
- 11.2 million with serious mental illness, 3.7 million of those are untreated
- 35.4 million with other mental illness, 22.9 million of those are untreated

...about 39.7 million (70 percent) did not receive treatment in the past year

Source: Substance Abuse and Mental Health Services Administration, National Survey on Drug Use and Health, 2017. | GAO-19-274

Notes: Adults with a substance use condition are adults classified in the National Survey on Drug Use and Health (NSDUH) as having a “substance use disorder.” Adults with serious mental illness are adults classified in NSDUH as having “any mental disorder that results in serious functional impairment.” Adults with other mental illness are adults with any mental disorder not classified as serious. Adults with untreated substance use conditions did not receive specialty substance use treatment in the past year; adults with untreated mental health conditions did not receive mental health services in the past year.

The numbers on the right side of the figure add to more than the numbers on the left side due to co-occurring behavioral health conditions.

While NSDUH does not include data on the prevalence of behavioral health conditions among active military personnel or homeless individuals, among other populations, there are some other sources of data on these populations. For example, the Department of Defense conducted a survey aimed at understanding health-related behaviors of active-duty service members. The 2015 survey estimated that 35 percent were engaged in what the survey classified as probable hazardous drinking or had a probable alcohol use disorder.11 This survey also found

When considering prescription drugs, the survey found that 4.1 percent of active-duty service members used them without a prescription and 0.9 percent used more than prescribed. The survey also found that almost 18 percent of active-duty service members experienced one of three probable mental health problems—depression, generalized anxiety disorder, or post-traumatic stress disorder. The prevalence of the latter two conditions was higher in the active-duty service population than in the general population (14.2 and 8.5 percent for service members and 3 and 4 percent, respectively, for the general population). The survey also found that 36 percent of those who said they had needed mental health care in the past year had not received it; the survey did not ask about treatment for substance use disorders. The Department of Housing and Urban Development also conducts a survey of homeless persons on a single night each year. It found that 20 percent of the 553,742 homeless individuals surveyed in 2017 had a serious mental illness, while 16 percent had a substance use condition. The survey did not collect any information about behavioral health treatments this population may have received.

Behavioral Health Treatments

Treatment for behavioral health conditions can help individuals reduce or stop substance use, manage their symptoms, improve their quality of life, and avoid the potential consequences of untreated conditions, such as worsening health, reduced educational attainment, loss of employment, and involvement with the justice system. (See app. IV for a discussion of costs related to behavioral health conditions other than health care costs.) Behavioral health treatments include an array of options ranging from less to more intensive, and may include prevention services, screening and assessment, outpatient treatment, inpatient treatment, and emergency services for mental health and substance use conditions. Prescription drugs may also be included as part of treatment. Supportive services,

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12The survey defined each of the mental health conditions as "probable."

13The Department of Housing and Urban Development’s survey defined serious mental illness as a severe and persistent mental illness or emotional impairment that seriously limits the ability to live independently for either a long-continuing or indefinite duration and could be improved with the provision of more suitable housing conditions. The survey defined substance use condition as a substance abuse problem (alcohol abuse, drug abuse, or both) that is long-continuing or indefinite duration, substantially impedes the ability to live independently, and could be improved by the provision of more suitable housing.
designed to help manage behavioral health conditions and maximize the potential to live independently in the community, include employment, housing, and other supports. SAMHSA has developed a working definition of recovery, the guiding principles of which note that there are multiple pathways to recovery based on such things as individual strengths, needs, preferences, experiences, and cultural backgrounds.\footnote{Substance Abuse and Mental Health Services Administration, SAMHSA’s \textit{Working Definition of Recovery: 10 Guiding Principles of Recovery}, PEP12-RECDEF (2012).}

No single treatment is effective for all adults with a specific behavioral health condition, and recovery is not a guaranteed outcome from treatment, even if it is effective. SAMHSA’s definition of recovery states that mental health recovery is non-linear, characterized by continual growth and improved functioning that may involve setbacks. Likewise, both the National Institute on Drug Abuse and the Surgeon General note that substance use conditions are similar in course, management, and outcomes to chronic physical illnesses—such as hypertension, diabetes, and asthma—in that there is no cure, but the condition can be managed.\footnote{See https://www.drugabuse.gov/publications/drugs-brains-behavior-science-addiction/treatment-recovery (accessed August 7, 2018) and U.S. Department of Health and Human Services, Office of the Surgeon General, \textit{Facing Addiction in America}.} The chronic nature of these conditions means that for some people, relapse can be part of the recovery process. The National Institute on Drug Abuse notes relapse rates for substance use conditions (about 40 to 60 percent) are similar to rates for chronic physical health conditions such as hypertension and asthma (about 50 to 70 percent). As such, the Institute notes that substance use relapse—similar to relapse for other chronic conditions—should be viewed as an indication that resumed, modified, or new treatment may be necessary.
The 2017 NSDUH data show that the vast majority of adults with untreated behavioral health conditions did not receive treatment for their condition because they did not perceive a need for it. Specifically, NSDUH data show that an estimated 94 percent (or 16.2 million) of adults who needed but did not receive specialty substance use treatment did not perceive a need for treatment. Similarly, an estimated 82 percent (or 21.7 million) of adults with untreated mental health conditions did not perceive a need for mental health services. As shown in figure 3, adults with serious mental illness were much more likely than those with other mental illness to perceive a need for mental health services.

16 Included in both the 16.2 million and 21.7 million estimates are about 2.7 million adults with co-occurring conditions who were untreated for one or both of their conditions and did not perceive a need for either type of treatment. According to SAMHSA officials, because NSDUH measures perceived need for treatment differently for substance use and mental health conditions, the two estimates cannot be combined to produce a total number of adults with untreated behavioral health conditions who did not perceive a need for treatment.
Figure 3: Perceived Need for Treatment among Adults Aged 18 or Older with Substance Use or Mental Health Conditions Who Did Not Receive Treatment in Past Year, 2017

Substance use condition  
(17.2 million untreated)  

94%  
(16.2 million)  

6%  
(1.0 million)  

Serious mental illness  
(3.7 million untreated)  

57%  
(2.1 million)  

43%  
(1.6 million)  

Other mental illness  
(22.9 million untreated)  

85%  
(19.6 million)  

15%  
(3.3 million)  

Estimated 39.7 million adults with behavioral health conditions who did not receive treatment in past year

Perceived a need for treatment

Did not perceive a need for treatment

Source: Substance Abuse and Mental Health Services Administration National Survey on Drug Use and Health, 2017. | GAO-19-274

Notes: Adults with a substance use condition are adults NSDUH classified as having a “substance use disorder.” Adults with a mental health condition are adults NSDUH classified as having “any mental illness.” Adults with serious mental illness are adults classified in NSDUH as having “any mental disorder that results in serious functional impairment.” Adults with other mental illness are adults with any mental disorder not classified as serious. Adults with untreated substance use conditions did not receive specialty substance use treatment in the past year; adults with untreated mental health conditions did not receive mental health services in the past year.

Each pie includes adults with co-occurring behavioral health conditions who are also included in at least one of the other pies. For the estimated number and percentage of adults who perceived a need for treatment, margins of error at the 95 percent confidence level are plus or minus 17 to 18 percent for those with substance use conditions and plus or minus 10 to 12 percent for those with serious mental illness. For the number of adults with serious mental illness who did not perceive a need for treatment, the margin of error at the 95 percent confidence level is plus or minus 13 percent. For all other numbers and percentages, the margins of error at the 95 percent confidence level are within plus or minus 10 percent.

Based on studies we reviewed, our discussions with experts at our meeting, and interviews with stakeholders, we identified several possible reasons that individuals with behavioral health conditions may not perceive a need to obtain treatment for their condition. These reasons include:

- Inability or unwillingness to recognize they have a behavioral health condition. Experts, stakeholders, and studies suggest there may be several reasons individuals with behavioral health conditions do not recognize they have a condition requiring treatment, such as
• Low mental health literacy. Experts told us that individuals may lack knowledge about mental health conditions and treatment options and therefore not recognize that their symptoms indicate a condition that could benefit from treatment.

• Difficulty of distinguishing substance use from dependence or abuse. Experts observed that recreational alcohol or drug use may increase gradually, making it difficult for people to recognize when their use has crossed the line into dysfunction, particularly with alcohol use, since it is legal and more socially acceptable than illicit drug use.

• Less severe symptoms. Studies have found that individuals with behavioral health conditions who report fewer symptoms or less psychological distress are less likely to see a need for treatment. As one expert stated at our meeting, “people go to treatment when they’re in pain.” Some may not recognize that they need treatment until their condition has serious consequences. For example, one study found that adults who did not have recurrent alcohol-related legal problems were much less likely to perceive a need for treatment than those who had such problems.

• Effect of the illness on perception. Experts and stakeholders noted that a reduced capacity to perceive one’s illness—known as anosognosia—may be a symptom of certain serious mental illnesses.

• Denial. People may be unwilling to admit even to themselves that they have a substance use problem.

• **Pessimism about treatment effectiveness.** Experts and stakeholders told us that some individuals do not report a need for behavioral health treatment because they believe it to be ineffective.

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17For example, one study found that individuals with substance use conditions who met fewer criteria for dependence or abuse—including such symptoms as withdrawal or failure to fulfill obligations—were less likely to perceive a need for treatment compared with those who met more criteria. See S. L. Hedden, and J. C. Gfroerer, “Correlates of Perceiving a Need for Treatment among Adults with Substance Use Disorder: Results from a National Survey,” *Addictive Behaviors*, vol. 36, no.12 (2011).


19For example, see P. A. S. Dare and L. Derigne, “Denial in Alcohol and Other Drug Use Disorders: A Critique of Theory,” *Addiction Research & Theory*, vol. 18, no. 2 (2010).
This belief may stem from lack of information about the efficacy of various treatments, prior negative experiences with treatment, or, as one expert stated, knowledge that certain conditions, such as post-traumatic stress disorder, are difficult to treat.

- **Preference for self-reliance.** Experts, stakeholders, and studies indicate that some individuals believe they can handle their behavioral health condition on their own and prefer to do so. For example, among active military personnel surveyed in 2015, the most common reason for not seeking needed mental health services—cited by over 60 percent of those surveyed—was a desire to handle the problem on their own.²⁰

While most adults with untreated behavioral health conditions do not perceive a need for treatment, millions do perceive a need but still do not obtain treatment. In the 2017 NSDUH, adults with untreated behavioral health conditions who perceived a need for treatment—an estimated 1 million of those with untreated substance use conditions and 4.9 million of those with untreated mental health conditions—cited a variety of reasons for not obtaining treatment in the past year.²¹ About one-third to one-half of adults in each group cited reasons that fall into four categories: cost; stigma; access challenges, such as not knowing where to go for services; and treatment not being a priority. About one-tenth or fewer in each group cited reasons in a fifth category, a belief that treatment would not help, or some other reason.²² Studies we reviewed, experts at our meeting, and interviews with stakeholders provide insight into the various reasons cited by survey respondents.

²⁰Meadows et al., 2015 Department of Defense Health Related Behaviors Survey.

²¹Adults with co-occurring conditions who were untreated for one or both of their conditions and who perceived a need for treatment are included in both the 1 million and 4.9 million reported here.

²²For all categories of reasons, except “did not think treatment would help” and “other reasons,” estimates have margins of error at the 95 percent confidence level of plus or minus 17 to 27 percent for those with substance use conditions and plus or minus 10 to 18 percent for those with serious mental illness. For the categories of “did not think treatment would help” and “other reasons,” the margins of error at the 95 percent confidence level are plus or minus 75 to 89 percent for those with substance use conditions, 18 to 25 percent for those with any mental illness, and 29 to 32 percent for those with serious mental illness. For any specific reasons reported within the categories, margins of error at the 95 percent confidence level are plus or minus 23 to 36 percent.
Among NSDUH respondents with behavioral health conditions who reported that they did not receive treatment for their condition in the past year despite perceived need, about two-fifths of those with substance use conditions and one-half of those with mental health conditions cited cost-related reasons, such as a lack of insurance. Adults with serious mental illness were more likely than those with other mental illness to cite cost as a reason for not receiving services. Studies we reviewed, experts at our meeting, and stakeholders we interviewed identified several reasons that obtaining and maintaining insurance coverage may be particularly difficult for people with behavioral health conditions. For example, one stakeholder noted that individuals with mental health conditions may have trouble finding employment, which could provide insurance coverage, and also that they may not qualify for Medicaid. Further, individuals who do have health insurance may have difficulty maintaining it if, for example, their symptoms interfere with basic functions such as paying premiums on time or they are homeless and have nowhere to receive mail or other communications about insurance coverage or disability determinations.

For people who maintain insurance coverage, experts at our meeting pointed to high deductibles and copays in some private insurance plans as potentially posing financial barriers to treatment. One study found that copays for substance use treatment were as high as $60 to $70 per outpatient visit and $2,500 per inpatient stay in some private insurance plans. Some studies have found that individuals with Medicaid coverage—with generally lower copays and deductibles—were more likely to receive substance use treatment than those with private insurance. Experts also noted that some health care providers may be unwilling to accept insurance and insurance coverage may be limited for certain types of behavioral health care, which can lead to higher out-of-

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23NSDUH included three cost-related reasons for not obtaining treatment: (1) insurance did not cover any behavioral health treatment or did not pay enough; (2) could not afford cost; and, (3) with regard to substance use treatment specifically, no health care coverage.


25Findings regarding the impact of insurance coverage on substance use treatment are mixed, with several studies finding that people without insurance access treatment at greater or the same rate as those who are insured, possibly due to the availability of publicly-funded treatment for the uninsured. See E. Bouchery, R. Morris, and J. Little, Examining Substance Use Disorder Treatment Demand and Provider Capacity in a Changing Health Care System: Initial Findings Report (Princeton, N.J.: Mathematica Policy Research, 2015).
pocket costs. These observations are consistent with recent research. For example, a nationwide study found that, compared to medical and surgical care, individuals were much more likely to obtain behavioral health care outside of insurance networks, which generally entails higher out-of-pocket costs.26

Stigma

Among NSDUH respondents with untreated mental health conditions who perceived a need for treatment, more than two-fifths of those with a serious mental illness reported stigma as a reason for not receiving treatment in the past year. The respondents cited concerns that treatment might cause others to have a negative opinion of them, for instance, or might lead to their being committed to a psychiatric institution or being forced to take medicine.27 According to a report by the National Academies, mental health and substance use conditions are among the most highly stigmatized health conditions in the United States.28 A national poll conducted in 2013 found that 46 percent of respondents believed that “people with serious mental illness are, by far, more dangerous than the general population,” and only 33 percent were willing “to have a person with serious mental illness as a neighbor.”29 The National Academies’ report also indicated that individuals with substance use conditions are widely perceived to be dangerous and unpredictable, as well as at fault for their condition. About one in five NSDUH respondents with untreated substance use conditions who perceived a need for treatment—and about one in six with a serious mental illness—cited concerns about possible negative effects on their job as a reason for not receiving treatment. A separate survey funded by the Department of Defense indicated that such concerns were even more prevalent among active-duty military personnel. Among those surveyed in 2015 who reported a need for mental health treatment, between 25 and 35 percent


27In addition to these two stigma-related reasons, NSDUH included three others: (1) might have negative effect on job; (2) did not want others to find out; and, (3) with respect to mental health services specifically, concerns about confidentiality.


reported that they had not received any in the past year due to fears that receiving treatment would harm their career, cause their leadership to have a negative opinion of them, or undermine co-workers’ confidence in them.  

Access challenges

Among NSDUH respondents with untreated behavioral health conditions who perceived a need for treatment, almost one-third of those with substance use conditions and almost one-half of those with mental health conditions reported that they did not obtain behavioral health treatment due to access challenges, the most common being not knowing where to go for care. Experts at our meeting observed that low-income adults may face more access challenges than others. For example, hourly wage workers may be unable to get time off from work for treatment, and those who are homeless may have to put other priorities, such as shelter, before treatment. Other access challenges stem from a lack of behavioral health treatment capacity or an uneven geographic distribution of services. For example, experts at our meeting cited difficulties individuals may face finding and accessing providers who offer medication-assisted treatment for substance use conditions, an issue on which we have previously reported. In addition, provider shortages in rural areas have been documented in multiple studies. One recent study, based on 2015 data, found that in the most rural counties, the per capita supply of psychiatric nurse practitioners was about one-half the supply found in metropolitan counties, and the per capita supply of psychiatrists and psychologists was about one-quarter that found in metropolitan counties. SAMHSA cites workforce shortages as a key driver of the unmet need for behavioral health services, with 55 percent of the counties

30Meadows et al., 2015 Department of Defense Health Related Behaviors Survey.

31NSDUH included four additional access-related reasons for not obtaining treatment: (1) no transportation, treatment too far away, or hours inconvenient; (2) did not have time; and, with regard to substance use treatment specifically, (3) did not find type of treatment wanted, and (4) no openings in program.

32GAO, Opioid Addiction: Laws, Regulations, and Other Factors Can Affect Medication-Assisted Treatment Access, GAO-16-833 (Washington, D.C.: Sept. 27, 2016). Experts at our 2018 meeting observed that some physicians certified to provide buprenorphine, one of the medications approved for use in treatment of opioid addictions, decline to be publicly listed as providers of the treatment and strictly limit their caseloads, possibly because individuals with substance use conditions need to be seen more frequently than other patients and can be a “difficult” population to treat.

About half of NSDUH respondents with untreated substance use conditions who perceived a need for treatment indicated that treatment was not a priority, citing one or more specific reasons in this category. In particular, about 40 percent of adults with substance use conditions who had not received treatment in the past year reported this was because they were not ready to stop using alcohol or illicit drugs. The NSDUH data also indicate that only about half of adults with untreated substance use conditions who perceived a need for treatment made an effort to get it in the past year.

While pessimism about the effectiveness of treatment may keep adults with behavioral health conditions from perceiving any need for treatment, it may also keep some who do perceive a need from seeking treatment. Among NSDUH respondents with untreated serious mental illness who perceived a need for treatment, 16 percent cited a belief that treatment would not help as a reason for not obtaining treatment. According to one stakeholder we interviewed, unsuccessful treatment can discourage or even traumatize people with mental illness, making them less likely to pursue treatment. Those with substance use conditions may also be less

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34Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Report to Congress on the Nation’s Substance Abuse and Mental Health Workforce Issues (Jan. 24, 2013).


36NSDUH included three reasons for not obtaining treatment that related to treatment not being a priority: (1) did not feel need for treatment at the time; (2) thought they could handle problem without treatment; and (3) with regard to substance use treatment specifically, not ready to stop using. Just over one-third of NSDUH respondents with untreated mental health conditions who perceived a need for treatment indicated that it was not a priority.

37Similarly, a longitudinal study based on data from the National Epidemiologic Survey on Alcohol and Related Conditions found that only about 15 percent of adults who perceived a need for help addressing their substance use reported 3 years later that they had gone anywhere or seen anyone for a reason related to their substance use in that period. However, this treatment rate was still significantly higher than that for adults who did not perceive a need for help (about 5 percent). See R. Mojtabai and R. M. Crum, "Perceived Unmet Need for Alcohol and Drug Use Treatments and Future Use of Services: Results from a Longitudinal Study," Drug and Alcohol Dependence, vol. 127 (2013).
likely to pursue treatment, at least in the short-term, if they doubt its effectiveness. According to a study of barriers to substance use treatment, individuals’ pessimism about treatment effectiveness was the only barrier shown to be significantly associated with individuals not obtaining substance use treatment over a 3-year period.\textsuperscript{38}

Available Research Is Limited and Does Not Estimate Overall Health Care Costs Associated with Untreated Behavioral Health Conditions

We found that there is no generally accepted estimate of all the health care costs associated with untreated behavioral health conditions, and methodological challenges and data limitations make it difficult to estimate these costs. Available research compares the health care costs of those who did not receive treatment for their behavioral health conditions to the costs of those who received treatment, and most studies we reviewed found that the health care costs associated with the former were higher.

Research on Untreated Behavioral Health Conditions Does Not Estimate Overall Health Care Costs, Reflecting Methodological Challenges and Data Limitations

Our work found that there is no overall, generally accepted estimate of all the health care costs associated with untreated behavioral health conditions. Specifically, the experts at our meeting did not identify—or discuss—any research that identifies a generally accepted estimate of all the health care costs associated with untreated behavioral health conditions, either overall or for any specific mental health or substance use condition. In addition, none of the 29 studies we reviewed as part of our literature review provided such an estimate.

Based on information from the experts at our meeting, stakeholders we interviewed, and research we reviewed, we found that several methodological challenges and data limitations make it difficult for researchers to estimate the health care costs associated with untreated behavioral health conditions.

Methodological challenges

Challenges defining the untreated population. Experts at our meeting told us that there are different ways of defining what treatment is for a behavioral health condition and therefore who is considered treated or untreated. For example, experts had different opinions about whether self-help programs, like Alcoholics Anonymous, are considered treatment because, though people utilize them as part of a continuum of care to

\textsuperscript{38}Mojtabai and Crum, “Perceived Unmet Need for Alcohol and Drug Use Treatments.”
help manage a behavioral health condition, they are not traditional health care interventions. Similarly, supportive services such as housing may help people initiate and stay in treatment for a behavioral health condition, but these services may or may not be considered treatment. Furthermore, experts noted that not all care is effective, and that some people who have had contact with behavioral health treatment providers should still be considered “untreated” if their care is of poor quality or not appropriate for their circumstances.

Challenges determining all of the relevant health care costs that can be associated with behavioral health conditions. Experts at our meeting told us that it can be challenging to determine which health care costs should be attributed to an untreated or treated behavioral health condition. For example, in cases where a person is being treated for a physical health condition but his or her behavioral health condition is undiagnosed or not the primary diagnosis associated with his or her visit, it is unclear whether the costs of the treatment for the physical health condition should be attributed or partly attributed to the behavioral health condition. Reflecting this challenge, the studies we reviewed often examined a limited portion of health care costs for people with untreated behavioral health conditions, making it difficult to develop a single overall estimate of the costs. Specifically, the studies we reviewed examined some portion of health care costs—such as the costs associated with inpatient care, outpatient care, emergency department care, prescriptions, or primary care, among others—and whether these costs changed after providing a treatment. However, when examining the health care costs associated with treating a behavioral health condition, one challenge is that the effects of any given treatment on different categories of health care costs can vary, with a treatment leading to both increases and decreases in costs. For example, one study we reviewed found that six months after providing treatment for substance use, average emergency department costs for the study population had fallen approximately 20 percent, while average inpatient costs had risen nearly 40 percent.39

Challenges generalizing from study results to a broader estimate of health care costs.

Studies that examine the health care costs associated with behavioral health conditions may not reflect what happens outside of the studies, according to the experts at our meeting. These experts, as well as stakeholders we interviewed, stated that it is unclear whether results from individual studies comparing treated and untreated adults with behavioral health conditions could be replicated if the treatment were provided to a larger population. Therefore, it is difficult to estimate how costs might change when increasing available treatment for behavioral health conditions. There are several reasons for this, according to experts and stakeholders.

- Study participants who receive treatment for behavioral health conditions may differ from others with the condition in important ways. In particular, experts and stakeholders noted that individuals who participate in studies of behavioral health treatment may have different treatment needs compared to others with behavioral health conditions; they may need more behavioral health interventions or they may need fewer. This in turn can make it difficult to use study results to estimate the overall health care costs associated with treating a behavioral health condition. A Washington state official noted, for example, that while studies in the state showed that treatment for substance use produced overall health care cost savings, cost savings were not expected to be as large, on average, when treatment was expanded to a larger population. This is in part because the larger population with access to the treatment would likely be healthier than the participants in the studies.

- Some studies we reviewed found that health care costs are lower for study participants who receive treatment for their behavioral health conditions; however, experts and stakeholders told us that outside of the study it is unclear how many individuals will actually seek and complete the treatment associated with the reduced costs. Experts noted that since there is not good information on some people with the most serious conditions, or who face other barriers such as homelessness, it is unknown how their costs would change if they received treatment.

- Experts at our meeting noted that even if treatment for a behavioral health condition is considered successful and symptoms are controlled, individuals may need continued treatment. Studies may not capture the ongoing costs of such continued treatment. Experts said that ongoing health costs are similar to the doctor’s visits and
medication necessary to manage certain chronic physical health conditions, such as asthma or diabetes.

- Experts told us that studies often primarily analyze results of those participants they have been able to follow and who remain in treatment. Outside of studies, it is harder to keep track of patients. If treatment is not completed, it may be less effective and therefore cost savings may not be realized.

Data Limitations

Experts at our meeting and stakeholders we interviewed identified some examples of limitations in existing data sources that also affect researchers’ ability to estimate the health care costs associated with untreated behavioral health conditions in adults. Experts and stakeholders offered ideas and suggestions for possible ways to begin addressing these limitations, as did a 2017 Interdepartmental Serious Mental Illness Coordinating Committee report.\(^{40}\) Even if these data limitations were addressed, our work suggests the methodological challenges described above would continue to make it difficult to estimate the health care costs of untreated behavioral health conditions.

**Multiple data sources are difficult to link.** Data on untreated behavioral health conditions and associated health care costs often come from multiple sources that, though useful individually, are difficult to link with each other and use together in a single study. For example, experts told us that data on health insurance claims, which include useful information on health care procedures and costs, may be available through a combination of state Medicaid programs and all-payer claims databases maintained by some states, but information from these separate sources can be challenging to link. Specifically, the experts stated that separate data sources may contain incomplete information or lack the identifiers necessary to link the sources together. Experts said that better integrating or linking data could improve available information, including information

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\(^{40}\)The Interdepartmental Serious Mental Illness Coordinating Committee was established under the 21st Century Cures Act to evaluate programs and services for people with serious mental illness and serious emotional disturbances. Pub. L. No. 114-255, § 6031, 130 Stat. 1033, 1217 (2016). The committee comprises representatives from 10 federal agencies and departments as well as non-federal members with experience with the mental health service system and knowledge of barriers that exist for people who are seeking help. This report includes information from their first meeting in August 2017 and ongoing dialogue of the committee members. See Interdepartmental Serious Mental Illness Coordinating Committee, *The Way Forward: Federal Action for a System That Works for All People Living With SMI and SED and Their Families and Caregivers*, (Dec. 13, 2017).
on the costs associated with untreated behavioral health conditions. For example, experts described possible benefits of linking SAMHSA’s NSDUH (which reports population estimates on the prevalence of and treatment for behavioral health conditions), SAMHSA’s Treatment Episode Data Set (which reports client-level behavioral health treatment data), and physical and behavioral health utilization and cost data from state Medicaid programs, while also acknowledging the difficulty of doing so. The experts cited a Washington state government agency’s actions linking multiple data sources—such as treatment data, Medicaid data, and other state data—as a successful example of data linkages at the state level. According to a Washington state official, the actions have helped the state develop behavioral health-related policies and performance measures.

Limitations exist in information about the prevalence of specific behavioral health conditions. Experts told us that not knowing how many people have specific behavioral health conditions makes it more difficult to determine the health care costs associated with these conditions when they go untreated. Data sources may not identify the number of people with depression or with anxiety, for example. Experts explained that data sources such as NSDUH and the National Epidemiological Survey on Alcohol and Related Conditions both provide useful information on the prevalence of specific substance use conditions. However, experts said that the sources focus on substance use and therefore do not provide comparable data on the prevalence of specific mental health conditions. In addition, experts also told us that some data related to the prevalence of mental health conditions has been useful in the past but is now no longer up to date. For example, experts

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41 The Treatment Episode Data Set is maintained by SAMHSA and comprises data on the demographic characteristics and substance use problems of people admitted to substance use treatment facilities.

42 A Washington state official told us that the state linked multiple data sources, including data on behavioral health, physical health, employment, criminal justice, and housing, to assess costs and benefits of various behavioral health treatment programs used in the state, despite challenges such as funding, data privacy, and changing technology that can affect states’ data linkage efforts.

43 The National Epidemiologic Survey on Alcohol and Related Conditions is a cross-sectional survey conducted by the National Institute on Alcohol Abuse and Alcoholism at the National Institutes of Health. It collected information on alcohol and drug use and disorders, related risk factors, and associated physical and mental disabilities. Wave 1 of the survey was fielded in 2001–2002. The survey was administered again in 2004-05 and 2012-13.
said that they previously used data from a mental health-focused supplement to the National Health Interview Survey that was conducted in 1999.44

**Limited data are available on the long-term costs for adults with untreated behavioral health conditions.** Experts at our meeting said that existing data sources do not provide adequate information on the health care costs of individuals with untreated behavioral health conditions over longer periods of time. They noted, for example, that some changes in health care costs may occur later due to the cumulative effects of an untreated behavioral health condition, making the time frame very important when considering costs. Experts also said that studies have a particularly difficult time tracking adults over time to obtain long-term data on the health care costs associated with their behavioral health conditions, because individuals may move around frequently, receive care through various health care payers (e.g., private insurance, Medicaid, etc.), and have periods when they go untreated. These factors can make it difficult to identify all of the health care costs associated with the individuals’ behavioral health conditions whether they are treated or untreated. For example, some of the studies we reviewed that looked at relatively extensive periods of time (e.g., 2 to 5 years) found that health care costs observed soon after treatment for a behavioral health condition differed from those observed over the long term. Experts noted that there is a need for more long-term data that could be used to research the course of mental illness and substance use conditions, including any treatment received.

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44The Centers for Disease Control and Prevention’s National Health Interview Survey, started in 1957, collects data on a broad range of health topics through personal household interviews. The U.S. Census Bureau serves as the data collection agency for the survey, which helps provide data to track health status, health care access, and progress toward achieving national health objectives.
While the research we reviewed does not provide an estimate of the overall health care costs associated with untreated behavioral health conditions, it does compare the costs associated with treating and not treating these conditions. A majority of the studies we reviewed (20 of 29) found that among study participants, health care costs were higher for those who did not receive treatment for their behavioral health condition compared with those who did. These studies examined various types of health care costs, including inpatient care, outpatient care, emergency department care, prescriptions, or primary care. Of the 29 studies we reviewed, 20 found that health care costs were higher for untreated adults than for adults who were treated, 6 found that health care costs were lower for untreated adults, and 3 reported either mixed results or no observable difference in health care costs between the two groups. (See figure 4.) In general, the studies were limited in scope—focusing, for example, on specific behavioral health conditions and their treatment, specific geographic areas, and the costs to specific payers (such as government programs or private insurers)—which precludes comparing study results or summing the various cost estimates. However, experts at our meeting told us that while these focused studies are limited in scope and applicability, their estimates of health care costs can be useful to policymakers.

45 For the studies we reviewed, we classified individuals as untreated if they did not receive the specific treatments being studied. They may have received other behavioral health treatments.

46 These types of studies are often referred to as cost-benefit or cost-effectiveness studies. These studies used various methods to calculate their cost estimates, including: a) comparing the health care costs of a group of adults who received treatment for a behavioral health condition to a separate group with the same condition who did not receive treatment; b) comparing the health care costs of one group of adults before and after they received treatment for a behavioral health condition; or c) modelling the effects treating adults for a behavioral health condition would have on health care costs. These studies typically defined “untreated” adults as people who did not receive the studied treatment during the course of the research.
Figure 4: Summary of 29 Studies GAO Reviewed on Health Care Costs Associated with Untreated Behavioral Health Conditions

<table>
<thead>
<tr>
<th>Study number</th>
<th>Behavioral health condition studied</th>
<th>Types of health care costs analyzed in study</th>
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<td>Inpatient care£</td>
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<td>Health care costs higher for adults who were not treated for their behavioral health condition</td>
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Study analyzed health care costs in this category
Mental health
Substance use

Source: GAO analysis. | GAO-19-274

*GAO reviewed 29 studies published from 1996 through 2017.
Inpatient care costs include services such as hospitalizations for either physical health or behavioral health conditions.

Outpatient care costs include services such as community-based mental health services.

Primary care costs include care by a primary care physician, general medical or physician services, or services provided at a primary care facility.

Studies we reviewed, experts at our meeting, and stakeholders we interviewed identified reasons why untreated behavioral health conditions may be associated with higher overall health care costs. Among the reasons for the higher costs are the following:

- **Untreated behavioral health conditions may be associated with other physical health conditions.** Stakeholders noted that adults who do not receive treatment for their behavioral health conditions may be more likely to experience other, often related, physical health conditions, which in turn have their own costs. Additionally, some studies we reviewed have concluded that when treatment helps adults manage their behavioral and physical health conditions more effectively, over time those adults reduced health care utilization and lowered their overall health care costs. For example, one study found that health care costs for adults who completed treatment were lowered after they sought care for other health care needs. ⁴⁷

- **Costs of acute care for untreated behavioral health conditions may be higher than the costs of ongoing treatment.** Experts told us that the health care costs associated with acute treatment for behavioral health conditions, such as the costs of hospitalizations, can be higher than the costs of ongoing treatment for the condition (e.g., weekly visits to a mental health professional). For example, one study of serious mental illness found that ongoing telehealth treatment may reduce the frequency of relapses that result in hospitalization. The study’s authors concluded that individuals who receive the telehealth treatment are also likely to experience lower health care costs. ⁴⁸


Another study found reduced hospitalizations associated with an early intervention for psychotic disorders.\textsuperscript{49}

Six of the 29 studies we reviewed found that health care costs overall were lower for adults who did not receive treatment for their behavioral health condition, compared with adults who did. Evidence suggests multiple possible reasons that health care costs for those who received treatment could be relatively high.

- Some studies concluded that adults who receive treatment for their behavioral health condition also obtain treatment for previously neglected physical health conditions, thereby increasing overall health utilization and costs.\textsuperscript{50}
- Other studies found, and experts at our meeting indicated, that some treatments for behavioral health conditions can be relatively expensive and therefore do not produce offsetting cost savings.\textsuperscript{51}
- Finally, stakeholders we interviewed told us that if an adult with a behavioral health condition is relatively healthy overall, treating that behavioral health condition is unlikely to produce cost savings.

In addition to the 29 studies we reviewed that compare the health care costs associated with treating versus not treating behavioral health conditions, we reviewed other studies—often referred to as cost of illness studies—identified by experts at our meeting and through our literature reviews. The experts told us these studies estimate the health care and other costs associated with behavioral health conditions for all individuals, though they generally do not focus exclusively on those with untreated


Experts told us that in some cases, most of the costs estimated in cost of illness studies might be associated with some untreated behavioral health conditions such as substance use conditions, particularly because only a small proportion of people with substance use conditions receive treatment. For example, a Surgeon General’s November 2016 report estimated that alcohol misuse, illicit drug use, misuse of medications, and substance use disorders cost the United States more than $400 billion in health care costs, lost workplace productivity, law enforcement and other criminal justice costs, and losses from motor vehicle crashes. However, this figure does not isolate the overall costs for those who are not treated and does not isolate the amount of health care costs specifically.

We provided a draft of this report to HHS, the Department of Defense, and the Department of Veterans Affairs. HHS and the Department of Defense provided technical comments, which we incorporated as appropriate. The Department of Veterans Affairs had no comments.

As agreed with your offices, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days from the report date. At that time, we will send copies to the Secretary of HHS and the Secretary of Defense, appropriate congressional committees, and other interested parties. In addition, the report will be available at no charge on the GAO website at http://www.gao.gov.


If you or your staff have any questions about this report, please contact me at (202) 512-7114 or deniganmacauleym@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix V.

Mary Denigan-Macauley
Acting Director, Health Care
Appendix I: Objectives, Scope, and Methodology

Objectives and Scope

Our report examined the following objectives: (1) reasons why some adults with behavioral health conditions do not receive treatment for their conditions, and (2) what is known about the health care costs associated with untreated behavioral health conditions in adults. For the purposes of this report, we focused on adults aged 18 and older with behavioral health conditions—that is, substance use conditions or mental health conditions.

We conducted this performance audit from October 2017 to February 2019 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Interviews with Agency Officials and Stakeholders

We interviewed numerous federal agency officials and stakeholders, whom we identified based on their relevant subject matter expertise to address both objectives. The federal officials we interviewed were from the Department of Health and Human Services—specifically the Substance Abuse and Mental Health Services Administration (SAMHSA), National Institutes of Health, Agency for Healthcare Research and Quality, Health Resources and Services Administration, and the Centers for Medicare & Medicaid Services—as well as the Departments of Defense and Veterans Affairs. The stakeholders we interviewed have expertise in a variety of topics, including substance use, mental health, and health economic research related to behavioral health conditions. Specifically, we interviewed officials from the National Association of State Alcohol and Drug Abuse Directors, the National Association of State Mental Health Program Directors, the National Association of Medicaid Directors, the National Alliance on Mental Illness, the American Hospital Association, the RAND Corporation, Washington State Department of Social and Health Services, and Washington State Institute for Public Policy.
Selecting and Meeting with Experts

To address both objectives, we also met with a group of experts. In June 2018, with the assistance of the National Academies of Sciences, Engineering, and Medicine (National Academies), we convened and moderated a 2-day roundtable of 13 experts to discuss various issues related to untreated behavioral health conditions that were related to both of our research objectives.¹ We contracted with the National Academies to help identify potential participants. Staff from the National Academies identified potential experts by, among other things, soliciting nominations from its membership, including those that represent the Board on Health Care Services and the Board on Behavioral, Cognitive, and Sensory Sciences. The experts were identified based on their expertise in the following areas:

- mental health, behavioral health, or substance abuse, including familiarity with the health care costs of adults with untreated conditions, health care benefits, or savings related to treating adults with these conditions;
- public health generally and related to mental health and substance use areas specifically;
- behavioral health policy, including public policy and sociology; and
- health care economics related to behavioral health conditions, including familiarity with or expertise in cost-benefit analysis, economic analysis, program evaluation, statistics, and measurement of costs or benefits and savings.

The experts we selected to participate in the meeting represented a broad range of viewpoints and knowledge. See appendix III for a list of experts, their institutions, and their areas of expertise.

Before finalizing the participation of the experts, we evaluated them for possible conflicts of interest. We considered conflicts of interest to be any current financial or other interest that might affect the objectivity of an expert’s statements during the meeting because it (1) could impair objectivity, and (2) could create an unfair competitive advantage for any person or organization. Of the 13 experts, one self-reported a potential conflict of interest related to their current work on opioids, but upon

¹The National Academies is a private, nonprofit organization that provides independent, objective analysis and advice to the nation and conducts other activities to solve complex problems and inform public policy decisions.
Appendix I: Objectives, Scope, and Methodology

To describe reasons why some adults with behavioral health conditions do not receive treatment for their conditions, we analyzed data from SAMHSA’s 2017 National Survey on Drug Use and Health (NSDUH), the most recent data available from the survey. This survey has been conducted periodically since 1971 and annually since 1990, and it is a major source of statistical information on the use of illicit drugs, alcohol, and tobacco and on mental health issues among members of the U.S. review, we determined that the work did not present a conflict. Further, the balance of experts represented in the meeting and the format of the meeting deemphasized the opinion of any one individual to support a significant finding, instead using the overall discussion as a collective body of information to answer our research objectives. We did not attempt to generate consensus among the experts, but rather sought a variety of information based on experts’ background and expertise.

The meeting was divided into topical sections, including discussions about:

- what is meant by the term “untreated,”
- identifying reasons some adults do not receive behavioral health treatment,
- the state of research on health care costs of adults with untreated behavioral health conditions,
- limitations and challenges in research on health care costs of adults with untreated behavioral health conditions,
- gaps in health care cost information, and
- potential actions to improve information.

The meeting was recorded and transcribed to ensure that we accurately captured the experts’ statements. Prior to and after the meeting, several experts provided us with published studies and information related to health care costs associated with untreated behavioral health conditions in adults, which we also reviewed.

This meeting of experts was planned and convened with the assistance of the National Academies to better ensure that a breadth of expertise was brought to bear in its preparation; however, all final decisions regarding meeting substance and expert participation were the responsibility of GAO. Any conclusions in this report are solely those of GAO.

Analysis of Data from SAMHSA’s National Survey on Drug Use and Health
Appendix I: Objectives, Scope, and Methodology

civilian, noninstitutionalized population aged 12 or older; however, our work focused only on adults aged 18 and older. Our analysis of NSDUH data was based largely on data tables published by SAMHSA in Results from the 2017 National Survey on Drug Use and Health: Detailed Tables (Detailed Tables). In addition, we requested and obtained from SAMHSA some additional tabulations of the 2017 survey data.

For the purposes of this report, we use the term “adults with a substance use condition” to refer to those that NSDUH classifies as having a “substance use disorder.” Substance use disorder is defined in NSDUH as meeting criteria for illicit drug or alcohol dependence or abuse based on definitions in the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). We use the term “adults with a mental health condition” to refer to those classified by NSDUH “with any mental illness.” NSDUH defines any mental illness as a diagnosable mental, behavioral, or emotional disorder that meets DSM-IV criteria (excluding developmental disorders and substance use disorders). The survey defines a serious mental illness as any mental disorder that results in serious functional impairment; other mental illness is any mental disorder not classified as serious.

Adults with untreated substance use conditions are adults identified in NSDUH as having a substance use disorder who did not receive treatment in the past year at a specialty facility (i.e., inpatient or outpatient drug and alcohol rehabilitation facility, inpatient hospital, or mental health center) to reduce or stop illicit drug or alcohol use, or for medical problems associated with illicit drug or alcohol use. Some of these adults may have received treatment at a non-specialty facility, such as an emergency room, private doctor’s office, self-help group, or prison/jail. However, we focused our analysis of NSDUH data on treatment at a specialty facility because some key estimates—such as the percentage of adults with untreated substance use conditions who perceived a need for

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2SAMHSA, Results from the 2017 National Survey on Drug Use and Health: Detailed Tables (Rockville, Md.: September 7, 2018).

3For more information on these criteria, see American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (4th ed.), Washington, D.C., 1994.

4All mental illness estimates in NSDUH are based on a predictive model and are not direct measures of diagnostic status.

5In 2017, an estimated 1.1 million adults reported receiving treatment only at non-specialty facilities.
adults who needed but did not receive substance use treatment at a specialty facility.

Adults with untreated mental health conditions are adults identified in NSDUH as having a mental illness who did not receive inpatient or outpatient mental health treatment or counseling or prescription medication for problems with emotions, nerves, or mental health in the past year. Adults with untreated co-occurring conditions are adults identified in NSDUH as having both a substance use disorder and a mental illness who did not receive one or both of the above described treatments in the past year (i.e., those who were untreated for at least one of their conditions).

For information on reasons why some adults with behavioral health conditions did not receive treatment in the past year despite perceived need, we referred to estimates in SAMHSA’s Detailed Tables, as well as to additional tables SAMHSA produced for us. The Detailed Tables include estimates of the number and percentage of adults aged 18 or older with various behavioral health conditions who cited each of 15 reasons for not obtaining treatment despite a perceived need for it. As some of the 15 reasons appeared related—for example “could not afford cost” and “health insurance does not cover mental health services”—we requested and obtained from SAMHSA new tabulations of these data, with the 15 reasons grouped into six categories: (1) cost, (2) stigma, (3) access challenges, (4) treatment not a priority, (5) did not think treatment would help, and (6) some other reason. SAMSHA provided these estimates for several groups of adults whose behavioral health conditions were untreated despite a perceived need for treatment, including those with a substance use disorder (which we term a substance use condition), those with serious mental illness, and those with any mental illness excluding serious mental illness (which we term other mental illness).

All estimates we present based on the NSDUH data have margins of error at the 95-percent confidence level of plus or minus 10 percent or less, unless otherwise noted.

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6 Those whose treatment/counseling status was unknown were excluded.

7 These categories are similar to those used in a SAMHSA report on mental health treatment. See SAMHSA, Racial/Ethnic Differences in Mental Health Service Use among Adults, HHS Publication No. SMA-15-4906 (Rockville, Md.: 2015).
To assess the reliability of the NSDUH data, we reviewed relevant documentation and interviewed knowledgeable SAMHSA officials. We determined that the data were sufficiently reliable for our reporting purposes. We also obtained feedback from SAMHSA officials on our presentation of the NSDUH data including figures and notes.

To further address the first objective, we conducted a review of research literature for information about why some adults with untreated behavioral health conditions do not perceive a need for treatment, as well as why some of those who do perceive a need for treatment do not obtain it. We identified articles and reports in a number of ways. First, we conducted structured searches of two databases, Scopus and ProQuest, to identify original research published in the United States from January 2008 through June 2018 that addressed these topics. Our search terms included various descriptors for behavioral health conditions, such as “substance abuse” and “mental illness,” as well as terms related to obtaining treatment, such as “help seeking behavior” and “insurance.” Because active military personnel are not included in NSDUH, we also searched for similar articles focused on this population. One analyst screened the resulting citations for relevancy in order to identify full-text articles for further review. In screening, we sought to identify articles that (1) were focused on U.S. adults aged 18 or older with behavioral health conditions and (2) provided insight into why some adults with these conditions do not perceive a need for treatment or do not obtain it.

We identified additional articles through internet searches, through review of the bibliographies of articles we had already obtained; and through searches of the websites of government agencies, including SAMHSA, the Agency for Healthcare Research and Quality, and the National Institutes of Health. While these articles do not represent the universe of relevant studies, we believe they are suitable for our purposes, to provide insight into why some adults with behavioral health conditions do not receive treatment.
To further address the second objective, we conducted a literature review and analyzed 29 studies that examined the health care costs of adults with untreated behavioral health conditions. We identified the studies in a number of ways.

- First, we conducted an informal search for studies addressing issues related to untreated behavioral health, mental health, and substance use. This included internet searches for relevant scientific studies and government publications.

- Second, we asked all stakeholders we interviewed if they could suggest studies that we should review. For both of these first two approaches, we identified the original sources of data cited in the studies if they were not already identified in the study, and we also looked at any studies cited by these studies that appeared to be relevant to our objectives.

- Third, in April 2018, we conducted a formal literature search to look for additional studies that cited the relevant studies we already identified through the first two approaches above. The goal of this literature search was to identify more recent literature.

- Fourth, in April 2018, we conducted a formal literature search of several bibliographic databases, including MEDLINE, PsycINFO, and Scopus, to identify books and academic, government, think tank, and trade literature, using search terms related to health care costs for untreated behavioral health conditions.

- We also asked the experts we met with to review an initial list of studies for ones we may have missed or ones they had concerns about.

These searches identified 440 studies. Two analysts independently screened each study using the following criteria to determine whether it met the scope of the review.

- The study was the original source of the data reported. If we determined a study contained methodology that met our criteria but was not the original source of the data, we made every effort to obtain that original source.

- The study included adults.

8These types of studies are often called cost-benefit or cost-effectiveness studies.
Appendix I: Objectives, Scope, and Methodology

- The studied adults had a behavioral health condition (mental health or substance abuse or both). We included alcohol as a substance use condition. We did not include studies that examined tobacco as a substance use condition.

- The study was in a peer-reviewed journal, a state or federal publication, or published by a known think tank. We did not include studies from interest groups.

- The study included a group of adults with behavioral health conditions who did not receive treatment. Studies could examine this group before and after treatment, compare this group to a separate group with the same condition who received treatment, or prospectively model the effects on costs if this group were to receive treatment.

- The study assessed health care costs, in terms of either spending or utilization. Some studies reported health care costs in terms of dollars spent or cost of health care insurance claims, while others examined levels of health care system utilization, such as the number of visits to an emergency department, without determining a dollar cost for that utilization. Either approach met our criteria.

A research methodologist reviewed the studies selected by the analysts to make sure that the chosen studies used sound and reliable methods and to identify any obvious flaws. In addition, because we initially identified multiple studies from one state agency, we worked with that agency’s director of research to identify which of them were duplicative of others, and we only retained the unique studies.

Based on this process, we identified 29 studies for our final review, which were published from 1996 through 2017. While these studies do not represent the universe of studies of health care costs for adults with untreated behavioral health conditions, we believe they are suitable for our purposes to provide an overview of the general approaches used to study these costs, highlight limitations and challenges, and serve as a basis for discussing the general state of the literature.

To analyze the 29 selected studies, we used a structured format to identify (1) the behavioral health condition studied, (2) the geographic area of the study, (3) the treatment being studied, (4) the types of health care costs studied, (5) the methodology used, (6) the payer of the health care costs studied, (7) the overall direction of the observed difference in health care costs (if any) between the untreated and treated adults studied, and (8) the challenges and limitations noted by the authors.
We also reviewed other studies related to cost of illness. According to experts at our meeting, these studies estimate health care and other costs associated with behavioral health conditions, though they generally do not focus exclusively on individuals with untreated conditions. We identified some cost of illness studies during our search for studies on health care costs as described above. We also reviewed cost of illness
Appendix II: Bibliography

This bibliography contains citations for the 29 studies of health care costs for adults with untreated behavioral health conditions we reviewed. (See appendix I for more information on how we identified these studies.) Following the citation, we include the study numbers that we used to reference the study earlier in this report in figure 5.


Parthasarathy, Sujaya, Jennifer Mertens, Charles Moore, and Constance Weisner. "Utilization and Cost Impact of Integrating Substance Abuse Treatment and Primary Care." *Medical Care*, vol. 41, no. 3 (2003): 357-367. (Study 8)


# Appendix III: Participants in GAO’s Meeting with Experts on Untreated Behavioral Health Conditions in Adults

## Table 1: Participants in GAO's Meeting with Experts on Untreated Behavioral Health Conditions in Adults, June 2018

<table>
<thead>
<tr>
<th>Expert</th>
<th>Affiliation</th>
<th>Discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ellen Bouchery, M.S.</td>
<td>Mathematica Policy Research</td>
<td>Studies of cost of illness, treatment system, access to treatment, Medicaid spending for behavioral health, health economics</td>
</tr>
<tr>
<td>Susan Busch, Ph.D.</td>
<td>Yale University</td>
<td>Health economics, access to mental health and substance use disorder treatment</td>
</tr>
<tr>
<td>Robin Clark, Ph.D.</td>
<td>University of Massachusetts</td>
<td>Health economics, health policy and services research, costs of behavioral health conditions (including severe mental illness and opioid use)</td>
</tr>
<tr>
<td>Anita Everett, M.D.</td>
<td>Substance Abuse and Mental Health Services Administration, Department of Health and Human Services</td>
<td>Chief medical officer of federal agency, community psychiatrist, research on access and quality of services for people with serious mental illness</td>
</tr>
<tr>
<td>Rachel Garfield, Ph.D.</td>
<td>Henry J. Kaiser Family Foundation</td>
<td>Medicaid coverage for low-income individuals, political economics, access and barriers to care</td>
</tr>
<tr>
<td>Rick Harwood</td>
<td>National Association of State Alcohol and Drug Abuse Directors</td>
<td>Cost of illness studies, cost offset studies, alcohol use, drug use, mental illness</td>
</tr>
<tr>
<td>Michael Hirsch</td>
<td>Washington State Institute for Public Policy</td>
<td>Meta-analysis and cost-benefit analysis, including analyses of behavioral health interventions</td>
</tr>
<tr>
<td>Lynn Kovich</td>
<td>Pennsylvania Office of Mental Health and Substance Abuse Services</td>
<td>State- and county-level behavioral health services, direct work with behavioral health patients (including mental illness, intellectual disabilities, homelessness)</td>
</tr>
<tr>
<td>Tami Mark, Ph.D.</td>
<td>RTI International</td>
<td>Health economics, estimates of federal spending on substance use and mental health care, costs of illness studies on substance use (including opioids) and mental health</td>
</tr>
<tr>
<td>John McIlveen, Ph.D., LMHC</td>
<td>Oregon Health Authority</td>
<td>State oversight of opioid treatment programs, substance abuse research, clinical work, public policy</td>
</tr>
<tr>
<td>Ted Miller, Ph.D.</td>
<td>Pacific Institute for Research and Evaluation</td>
<td>Health economics, costs of substance abuse, costs of crime</td>
</tr>
<tr>
<td>Robert Rosenheck, M.D.</td>
<td>Yale University</td>
<td>Psychiatry, public health, mental health program evaluation, cost-effectiveness studies</td>
</tr>
<tr>
<td>Gary Zarkin, Ph.D.</td>
<td>RTI International</td>
<td>Costs and cost-benefit analysis related to substance use conditions, including opioid use</td>
</tr>
</tbody>
</table>

Source: GAO | GAO-19-274
Appendix IV: Other Costs Associated with Untreated Behavioral Health Conditions

In addition to health care costs that adults may incur when they have an untreated behavioral health condition, there are also a number of other costs associated with these conditions. The World Health Organization has noted that part of the economic burden from mental health conditions is measurable, such as health and social service needs, lost employment and reduced productivity, impact on families and caregivers, crime and public safety, and premature mortality. A report prepared for the Centers for Disease Control and Prevention also discusses the costs from excessive alcohol consumption in terms of productivity losses, as well as from crime, motor vehicle crashes, fire damage, and fetal alcohol syndrome. Below we discuss a number of the measurable costs that have been discussed and studied in the literature we reviewed or in prior GAO reports.

**Productivity Losses** – Productivity losses stem from work that was not done, but would have been done in the absence of a behavioral health condition. In general, the value of this lost work can be calculated based on the expected salary or wages that would have been associated with the work. These estimates sometimes also include the value of employee benefits and taxes. These losses to productivity come from work-related problems associated with behavioral health conditions, including absenteeism, short-term morbidity, long-term disability, impaired productivity, mortality and premature death, homelessness, as well as losses while hospitalized or institutionalized—including while incarcerated, such as for crimes related to the behavioral health conditions. It has been suggested that excessive alcohol consumption can interfere with an individual’s ability to gain employment due to impairments in their willingness or ability to find a job and work. For example, for people with serious mental illnesses, a portion of their earnings losses may reflect lower earnings compared with those who do

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3Bouchery, Simon, and Harwood, *Economic Costs of Excessive Alcohol Consumption*. 
Appendix IV: Other Costs Associated with Untreated Behavioral Health Conditions

not have these illnesses.\textsuperscript{4} Similarly, people with depression may also experience greater absenteeism or reduced performance compared with those without depression.\textsuperscript{5}

**Crime-Related Losses and Criminal Justice System Costs** – These costs are incurred when people with untreated behavioral health conditions commit crimes or become involved with the criminal justice system. Crime-related losses include losses to the productivity of crime victims, such as those stemming from lost days at work for themselves or for family members due to injuries, time spent cooperating with police, time testifying in court, and time spent replacing stolen or damaged property. Criminal justice system costs may include costs to police, courts—such as the costs of adjudication—and correctional institutions, including the cost of incarceration in jail or prison. In our prior work, we have reported on the challenges related to estimating the cost of crime, including both the tangible and intangible costs, as well as costs that are a direct result of crime, and costs in anticipation of and in response to crime.\textsuperscript{6} We have also reported on challenges tracking costs related to incarcerating or providing mental health care services to inmates with serious mental illness.\textsuperscript{7}

**Public Income Support Payments** – If people with untreated behavioral health conditions are unable to work or have reduced earnings, then they may be more likely to receive public income support payments.\textsuperscript{8} Therefore, there are costs in Social Security Disability Insurance payments and Supplemental Security Income cash assistance, food stamps, and public housing funded by the government.


Appendix IV: Other Costs Associated with Untreated Behavioral Health Conditions

**Motor Vehicle Crashes** – Behavioral health conditions—specifically those associated with misuse of alcohol and other drugs—are a significant cause of motor vehicle crashes, including those resulting in death. In addition to medical and productivity losses, motor vehicle crashes can lead to costs related to insurance, legal costs, travel delays, and property damage, including damage to roadways.

**Fire Damage** – It has been estimated that more than 40 percent of fire-related deaths and 5 percent of property damage from fires are attributable to alcohol intoxication.

**Family Impacts** - Family members often bear much of the financial burden associated with another family member's behavioral health condition. The World Health Organization reports that families bear the negative impact of stigma and discrimination, the stress of coping with the behavior itself, as well as the disruption of household routines and restriction of social activities. Families may also bear the costs for treatment when insurance is not available or does not cover the treatment. Other economic costs can be experienced when a family member cannot be fully productive because he or she is caring for an ill relative. Studies have found higher health care costs and a greater likelihood of health problems for family members of individuals with alcohol or other substance use conditions compared to those without relatives with substance use conditions.

**Other Costs** – Other costs associated with untreated behavioral health conditions include lost earnings for people with fetal alcohol syndrome,
special education costs associated with fetal alcohol syndrome, reduced educational attainment, homelessness, child abuse and neglect, and foster care.\textsuperscript{14}

Appendix V: GAO Contact and Staff Acknowledgments

<table>
<thead>
<tr>
<th>GAO Contact</th>
<th>Mary Denigan-Macauley, (202) 512-7114 or <a href="mailto:DeniganMacauleyM@gao.gov">DeniganMacauleyM@gao.gov</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff</td>
<td>In addition to the contact named above, Will Simerl (Assistant Director), Carolyn Feis Korman (Analyst-in-Charge), La Sherri Bush, Nancy Fasciano, Andrew Furillo, Jack A. Reeves, and Chris Woika made key contributions to this report. Also contributing were Muriel Brown, Leia Dickerson, Krister Friday, Walter Vance, Eric Wedum, Jennifer Whitworth, and Elizabeth Wood.</td>
</tr>
</tbody>
</table>
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