



In Their Own Words: How Fragmented Care Harms People with Both Mental Illness and Substance Use Disorder

AUGUST 2021



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Contents

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NORC at the University of Chicago is an objective nonpartisan research institution that delivers reliable data and rigorous analysis to guide critical programmatic, business, and policy decisions.

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The **California Health Care Foundation** is dedicated to advancing meaningful, measurable improvements in the way the health care delivery system provides care to the people of California, particularly those with low incomes and those whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.

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3 Introduction

3 About the Study Participants

Family Members and Close Friends of People with Dual Diagnoses

5 Background — A Fragmented System

6 Findings — How People with Dual Diagnoses Experience Care

Navigating the System and Coordination of Care
Interpersonal Relationships and Stigma
Race/Ethnicity

22 Despite All the Challenges, Most Are Improving

23 Conclusion — Moving Toward Integrated Care

24 Appendices

- A. How Structural Separation of Mental Illness and SUD Treatment Confounds Provider Organizations and Providers
- B. Demographics of All Interviewees

28 Endnotes

Introduction

For the 8.9 million American adults — about 500,000 Californians — with a dual diagnosis of mental illness and substance use disorder (SUD), it can be difficult to receive the fully coordinated and effective care they want and need. For people with low incomes, the barriers can be even higher. Many of the obstacles stem from the structural separation of mental health and SUD services into two different funding and delivery systems, but there are cultural, financial, and professional factors as well. A frequent result for patients is unnecessary suffering from their illnesses, while families and friends experience continuing stress as they search for effective help for their loved one.

To understand the experiences of Californians with dual diagnoses and the families and friends who support them, CHCF funded a study by social science research organization NORC at the University of Chicago. The researchers identified and interviewed people with in-depth personal or professional knowledge about dual diagnosis. Through these interviews, the project aimed to shed light on the real-life obstacles to treatment and good outcomes and to identify current practices that are working well.

NORC interviewed 93 people, including:

- ▶ 54 people with dual diagnoses and currently in treatment for mental illness, SUD, or both
- ▶ Nine loved ones — either family members or close friends — of people with dual diagnoses
- ▶ 20 direct care providers, five provider administrators, and five subject matter experts¹

The firsthand experiences of people with dual diagnoses and their family members and close friends are the central focus of this report. Interviews with direct care providers, provider administrators, and subject matter experts provide context and highlight structural and cultural impediments to care for people with dual diagnoses.² (See Appendix A for additional comments from this group.)

Dual Diagnosis Is Common

Co-occurrence is not unusual. Among people with substance use disorder (SUD), approximately one-third have a co-occurring mental health disorder.* Similarly, about 20% of people with a severe mental health disorder will also develop an SUD during their lifetime. Most people with a severe mental illness die at least 20 years earlier than would be expected, usually of preventable physical conditions. Unfortunately, only 7.4% of people with dual diagnoses receive treatment for both disorders, accessing treatment at lower rates than those without these comorbidities.[†]

* Wendy Holt, *Substance Use in California: A Look at Addiction and Treatment*, California Health Care Foundation, October 2018.

† Mary Ann Priester et al., "Treatment Access Barriers and Disparities Among Individuals with Co-occurring Mental Health and Substance Use Disorders: An Integrative Literature Review," *Journal of Substance Abuse Treatment* 61 (Feb. 1, 2016): 47–59.

About the Study Participants

The 54 people with dual diagnoses interviewed (adults 18 to 64) were recruited through treatment programs and all live in California households with incomes under 200% of the **federal poverty level**, or \$25,760 for a single person in 2021.³ They came from across the state and represented a mix of age, racial, ethnic, and geographic backgrounds. See Table 1 on the following page for a demographic breakdown. Five of the 54 interviews were conducted in Spanish.⁴

During the initial screening process, participants were asked to name their primary mental health diagnosis; over half (55%) cited depression. However, in subsequent interviews, they described a broader range of diagnoses including anxiety, bipolar disorder, schizophrenia, and post-traumatic stress disorder. Nearly half (47%) cited alcohol use as problematic, and many also said they had used methamphetamines (30%), marijuana, heroin, cocaine, and other drugs.

TABLE 1. INTERVIEWEES WITH DUAL DIAGNOSES, DEMOGRAPHICS

N = 54	NUMBER	PERCENTAGE
Race		
▶ African American / Black	10	19%
▶ Non-Hispanic White	24	44%
▶ Latinx/Hispanic	15	29%
▶ Native American	2	4%
▶ Other	3	6%
Sex		
▶ Male	38	70%
▶ Female	16	30%
Language in Which Interview Was Conducted		
▶ English	49	91%
▶ Spanish	5	9%
Age		
▶ 18 to 29	5	9%
▶ 30 to 39	19	35%
▶ 40 to 49	13	24%
▶ 50 to 59	13	24%
▶ 60 to 65	4	7%
CHCF Region		
▶ Northern & Sierra	17	31%
▶ San Joaquin	1	2%
▶ Other Southern California	3	6%
▶ Los Angeles	10	19%
▶ Inland Empire	18	33%
▶ Bay Area	5	9%

While there was no “typical” person with dual diagnoses, many interviewees reported that they had:

- ▶ Sought behavioral health (a term that includes mental illness and SUD) treatment through multiple avenues and settings over time; some had experienced involuntary hospitalizations.
- ▶ Experienced homelessness at some point, and many were currently living in shelters or supportive housing units or had lived in these settings in the past.
- ▶ Experienced incarceration, where some received limited behavioral health treatment; some had probation officers or courts order them to behavioral health treatment as a condition of their release or as part of a diversion program.
- ▶ Lost jobs or been unable to find employment due to their illness, criminal background, or because of stigma or transportation difficulties.
- ▶ Lost the support of or access to family members at some point (although some reported having maintained such support).
- ▶ Experienced trauma at some time, or many times, in their lives, including abuse, domestic violence, rape, and other traumatic experiences.
- ▶ Parents, siblings, or other family members who had suffered from mental health conditions or SUD.

Limitations of the participant group include an inability to interview as many Spanish-speaking people with limited English proficiency as desired, despite significant efforts in recruiting. (See Appendix B for detail.) By design, people of Asian descent were intentionally not recruited due to unique aspects of stigma in many Asian cultures documented in the literature.⁵ Additionally, because participants were largely recruited from treatment providers, it is likely that interviewees included a disproportionately high number of people who had experienced integrated or coordinated care compared to the universe of Californians with dual diagnoses.

Family Members and Close Friends of People with Dual Diagnoses

Among the nine family members and close friends of people with dual diagnoses interviewed, eight were women. These participants included five mothers, two sisters, one father, and one friend/partner. Most lived separately from their loved one with dual diagnoses. They supported their loved ones' recovery efforts by helping them navigate the health care system, providing shelter, looking after children, and/or serving as a sounding board. Among family members or close friends whose loved ones have severe mental illness and SUD, some have conservatorship and assist with activities of daily living, manage financials, and provide food and housing.

Direct Care Providers, Provider Administrators, and Subject Matter Experts

Among the 20 direct care providers who participated in interviews, a majority (13) were mental health providers, including psychiatrists, psychologists, marriage and family therapists, and licensed clinical social workers. The providers reported a high prevalence of dual diagnosis among their clients, most of whom were uninsured or had Medi-Cal coverage. All but two providers who worked with adult populations said the prevalence of dual diagnosis among their clients is greater than 50%. However, some believed there were high levels of undiagnosed mental health issues, which would bring the rate of dual diagnosis within their client population closer to 80% to 90%.

The provider administrators interviewed were trained as either mental health or SUD providers and also served in an administrative role at their organizations. The subject matter experts included people in academia, state government, and consulting who provided their knowledge of the issues surrounding treatment for people with dual diagnoses.

Background — A Fragmented System

The health care environment that people with dual diagnoses and their families and friends confront is fundamentally two systems with separate data and financing mechanisms, charting requirements, and privacy regulations. In some cases, providers in different settings within the same health care organization have different electronic health record (EHR) systems, with providers on the SUD side unable to access information from the mental health side and vice versa. A severe complicating factor is that the system that delivers physical health care is not typically integrated with either of the other systems — in effect presenting those seeking care with three separate environments, all with their own requirements and protocols.

Such structural segregation frustrates providers' ability to care for people with dual diagnoses (see details in Appendix A), but there are educational and cultural obstacles as well. Experts pointed out that mental health and SUD providers' training, experience, and opinions about the role of medication in treatment are often different, which can make it difficult for providers and their organizations to coordinate care or to treat people for both conditions. Cross-training of providers in both mental illness and SUD care is not common, and even when cross-training opportunities are available, some providers prefer to treat people only in the specialty in which they are primarily trained.

The impact of such segmentation on people with dual diagnoses cannot be overstated. It begins as soon as they enter treatment and their presenting symptoms are diagnosed. The interviews conducted for this report showed that this primary diagnosis determines not only where people enter care but also how they self-identify moving forward. This first diagnosis permeates their experiences with the health care system throughout their lives. Most of the interviewees with dual diagnoses focused their descriptions of care on a single diagnosis and its treatment; the researchers had to probe intensively to uncover experiences related to the other diagnosis. Providers and subject

matter experts concurred that the system's need for a primary diagnosis to bill for care was an administrative barrier that often prevented providers from treating a secondary diagnosis.

The primary diagnosis determines not only where people enter care, but also how they self-identify moving forward. It permeates their experiences with the health care system throughout their lives.

The impact of structural and cultural separation between systems can be especially severe for people who require inpatient care for either mental illness or SUD. Inpatient programs seldom address both problems or coordinate care after discharge. Those in inpatient settings for SUD are often required to stop taking their psychiatric medications, putting them in danger of recurrence of symptoms. Similarly, patients placed on a 72-hour psychiatric hold (5150) may not receive any SUD support or postdischarge care coordination for SUD treatment. For both groups of inpatients, the results of single-focus protocols can have unnecessary and painful consequences.

One provider described the impact on people with a dual diagnosis as a “vicious cycle” wherein people with serious mental illness stop taking their prescription medications to comply with SUD treatment rules, causing their mental health to deteriorate to the point where they cannot productively participate in their SUD treatment. This often leads to relapse and having to start over again.

Findings — How People with Dual Diagnoses Experience Care

The central focus of this report is on the experiences of the people with dual diagnoses and of the family members and friends closest to them. The findings from the project are organized in the following areas of impact on access and outcomes for people with dual diagnoses:

- ▶ Navigating the system and coordination of care
- ▶ Social determinants of health: employment, housing, criminal justice involvement
- ▶ Interpersonal relationships, stigma, and race/ethnicity

Navigating the System and Coordination of Care

Motivations for seeking treatment vary. Interviewees cited a number of factors that motivated them to seek treatment. Some described how a hospitalization, incarceration, estrangement from friends and family, or losing custody of a child was a wake-up call. Others said that having someone guide them through the system or having a role model motivated them to address their SUD and/or mental health issues. Some people said they decided to change after experiencing shame, denial, and not feeling supported by loved ones or providers.

“You have to want to find the help because a lot of people don’t. For me, in the past, I entered into a program just because my ex-woman would tell me, ‘You are really bad. You need help.’ Or the family would tell me, ‘You have to enter into treatment.’”

“From where I am now, I look back to see why it didn’t do me any good. It was because I always did it for another person. I never did it for myself.”

— 45-year-old Latinx man with dual diagnoses, Pasadena (interview conducted in Spanish)

People often don’t know how to get care. An issue commonly faced by people with dual diagnoses and their loved ones was not having information about treatment and service options. For people without housing, it is especially difficult. Various interviewees felt that navigating the system to find available and affordable care can be arduous.

Some described challenges understanding Medi-Cal and completing program applications. For example, an interviewee stated that they would have benefited from having more support to better understand administrative processes. Another said they had a problem “finding the person that knows how to answer the question.” A few interviewees said they got help navigating behavioral health systems from a variety of providers including drug and alcohol counselors, social workers, and therapists. One recounted how their therapist quickly referred them to an SUD clinic when they told the therapist they were not sure how to access SUD treatment. Others described relying on the emergency system. One person explained that the main way they seek help when they are having a mental health or SUD problem is to call 911, and then the operator refers them to the appropriate agency.

Loved ones of people with dual diagnoses described their difficulties in finding the right services. One mother recounted how she attended Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) meetings to determine if they were a good fit for her son. Another interviewee reported that the internet became her main information source to research treatment centers for her loved one, but said she was often unable to find options that were both affordable and convenient.

Distance from services is a serious complication for many people, especially in rural areas. A county behavioral health director and a peer specialist in different parts of the state each noted that there are no psychiatric wards or mental health facilities in certain remote parts of their counties. In each case, patients drive, or are driven by county staff, up to five hours, one-way, to the nearest psychiatric facility.

“I’ve been Googling, trying to find something that’s local. I was looking all day yesterday and the day before, when they took him to the hospital. There’s not really much out there. I’ve tried calling 211. And you know, they basically say, ‘Look on the Internet.’ There are places if you’ve got \$10,000 a month. But I haven’t got \$10,000.”

— Loved one of a person with dual diagnoses

Care is better when mental health and SUD providers work together. Interviews with patients as well as providers indicated that integrated care — concurrent treatment of SUD and mental illness at the same place by a multidisciplinary team — is the most effective model. When a single setting is not possible, interviewees observed that providers communicating and coordinating treatment from different locations can also be effective in treating dual diagnoses.

“The counselor would hold one-on-ones for an hour. They always asked, ‘How do you feel? What things have happened during the week? What goals do you have? What do you want to work more on? On your triggers? On your coping?’ We did exercises on how, when the thought to drink or consume comes to mind, how to deflect and turn that around . . . coping mechanisms. I have learned a lot. I am very grateful for that.”

— 45-year-old Latinx man in an integrated care treatment center receiving support for his alcohol and drug use and bipolar disorder, Pasadena (interview conducted in Spanish)

Several people described how their mental health and substance use providers across hospital inpatient, residential treatment programs, and outpatient settings effectively communicated with each other to facilitate care. One person expressed gratitude for this coordination because it relieved him from having to repeat himself over and over again.

Some people said their dual diagnosis treatment programs gave them important tools and knowledge in both small classroom settings and individual sessions with counselors. They reported gaining a better understanding of triggers, coping skills, and relapse

prevention. An interviewee noted that the classes he took in his dual diagnosis program helped him better grasp how his depression impacts his methamphetamine use: “For me it’s if I start sleeping a lot, I need to start knowing I’m going into depression. Depression had me using. So there are different ways that you start using in your mind before you even really pick up on it. It teaches me my triggers on what could set it off, or what’s setting it off and I don’t even know.”

“As soon as it became a problem, we reached out to the person’s addiction counselor to let them know that he’d fallen off the wagon.” The person had just graduated and was no longer going to be tested as regularly. “The counselor was really great and reached out to him right away, got him re-signed up in some classes, and I think that they set up a system where they were going to be checking in every week for several weeks. They were really quick and willing to jump on board with more thorough support.”

— Housing program manager / social worker at a mental health nonprofit, Napa County

In interviews, providers described how they individually took steps to coordinate care. For example, a mental health provider described collaborating on case management with a client’s drug and alcohol counselor through several phone conversations and by jointly attending a family meeting to discuss family dynamics and dysfunction. A therapist noted that she uses a confidential message and data-sharing system to send information back and forth with alcohol and drug services personnel.

Several interviewees gave examples of how their organization implemented multidisciplinary case management services and shared data with other providers.

A few mental health providers described processes for reaching out to a client's SUD case manager or counselor when the client is in distress. One clinic developed protocols to ensure that mental health clinicians assess patients for dual diagnoses and have the ability to add a secondary diagnosis code in the EHR system.

“Most treatment centers really minimize the dual-diagnosis aspect. They’ll advertise dual-diagnosis, and they’ll have therapists there that you have the option of seeing. But that’s about the extent of the dual-diagnosis treatment. Everything else is just about addiction.”

— 35-year-old White man with dual diagnoses,
Riverside County

A barrier to coordination are privacy laws, such as the 42 CFR Part 2 regulation, which require written patient consent for SUD information to be shared with other providers.⁶ Multiple providers noted how it can be cumbersome for providers and clients when release-of-information forms differ across organizations, resulting in multiple rounds of paperwork. One provider also noted how people with dual diagnoses sometimes are distrustful of sharing their SUD information with mental health providers and refuse to permit data sharing. This means their providers are limited in the amount and type of information they can share and receive from other providers, and coordination of patient care becomes more challenging.

Still, one provider reported that the loosening of the 42 CFR Part 2 regulation at the onset of the COVID-19 pandemic has proved helpful in coordinating patients' treatment with providers who do not treat SUD.⁷

Treatment for mental illness or SUD can lead to addressing other health care needs. Multiple people with dual diagnoses described getting basic preventive care like vaccines or physicals for the first time in years — or finally receiving medication or treatment for chronic conditions — when their SUD or mental health providers helped connect them to care for other health needs. For example, one person reported that their mental health and SUD providers connected them to needed cancer treatment. A person with diabetes, substance use, and bipolar disorder described how the coordination between their mental health and primary care providers led to the discovery that a mental health medication was affecting their blood sugar levels. Notably, across all interviews, only a small number of people described unmet physical health needs.

“Before I came [to a dual diagnosis treatment program] I wasn’t going to the doctor, so it’s working out better because now I have a primary care doctor . . . which means I won’t just be popping up in the emergency room for things. I have carpal tunnel in my arm that I just found out I’ll be getting surgery for. It’s been painning me for two years. No one’s figured it out because I’ve never had the same doctor.”

— 45-year-old Black woman with dual diagnoses,
San Mateo County

Medi-Cal coverage is perceived to be good, but access problems are serious. All the interviewees with dual diagnoses are covered by Medi-Cal, and most expressed satisfaction with the program. Several people said Medi-Cal was “great,” that they have “been really happy with Medi-Cal,” and that “they take care of me.” One person noted that Medi-Cal was very prompt in responding to her and that she was able to get coverage quickly.

“I’m satisfied with the Medi-Cal coverage. I am very thankful that they cover my medication, the treatment. It’s another opportunity to have another life, not normal — it will never be normal because I will always have that inside of me, that I am an alcoholic and addicted, but I can maintain it.”

— 45-year-old Latinx man with dual diagnoses,
Pasadena

However, despite satisfaction with coverage, the interviews surfaced complaints about the health care environment they faced. Many called it chaotic, describing how they were unable to access treatment due to missing staff or medication shortages. Others were disheartened because their providers had large caseloads and limited availability. One person said it took her over five weeks to be connected with a therapist who is only available for visits once every two months. Another described lengthy paperwork, consents, liability waivers, and a long psychosocial assessment every time they enter a new program.

A few people said they lost interest in residential treatment for SUD after waiting multiple weeks or months for a bed. One person was actively seeking residential treatment while experiencing homelessness, but found there was a long waiting list: “It was kind of a downfall for me because I couldn’t get in right away.” Several providers noted such delays can seriously impact people seeking SUD treatment — people who should get rapid access to care when they are ready. One described the need to “strike while the iron is hot.”

Some also described experiences of providers and insurance plans making care decisions that weren’t aligned with their preferences, such as being moved to another county for treatment, being discharged from treatment too early, or being denied services or medications. A few people with dual diagnoses and their loved ones recounted struggles with annual re-enrollment requirements and with finding local providers.

People also described frustration over Medi-Cal’s inability to provide other social services such as housing support. As of publication time, the California Department of Health Care Services is embarking on CalAIM (California Advancing and Innovating Medi-Cal), a multiyear plan to transform the Medi-Cal program and make it integrate more seamlessly with other social services, including housing support.⁸

Administrators, providers, and experts described hurdles such as Medi-Cal limits on allowable services or limits on total or daily treatments. However, under the state’s Drug Medi-Cal Organized Delivery System, the primary determining factor of whether a patient needs services is that patient’s medical need as determined by a doctor or other qualified health professional, in accordance with established guidelines.⁹ (There had been limits on residential treatment, but the state ended that policy with new guidance effective January 1, 2021.¹⁰ More than 90% of Medi-Cal enrollees live in a county participating in the Drug Medi-Cal Organized Delivery System.

The COVID-19 pandemic exacerbated challenges but also provided access benefits. Interviewees with dual diagnoses described the negative impacts of the pandemic on their mental health and substance use status. Worsening symptoms included depression, anxiety, and feeling isolated. A few people reported an increased urge to use drugs or alcohol, with one citing a relapse that led her to go to detoxification. Mental health and SUD providers also reported worsening symptoms in their patients with dual diagnoses that included increased self-harm, suicidal ideation, and self-medication. A mental health and an SUD provider both noted that the socializing and social supports people receive from in-person treatment were no longer occurring.

“I was doing great. I was going to AA meetings, I was going to church, I was meeting other people. And then coronavirus came and I had a relapse. I quit taking my psych meds, I started drinking. I got really depressed and I had to go to detox.”

— 60-year-old Black woman with dual diagnoses,
Riverside County

However, the research also pointed to ways that the pandemic-inspired relaxation of requirements around telehealth, confidentiality, and prescribing has supported greater access and care coordination. For example, rules were loosened around obtaining written consent for disclosing a patient’s SUD records when they transition to telehealth services.

“The meetings are ‘very beneficial.’ Of course, it’s online, on Zoom. But it’s still better than nothing because usually we do gatherings — we hang out in person and hug on each other and love on each other, but right now it’s just virtual hugs and kisses. But it’s pretty cool. It’s something we have to get used to, because for us it’s recommended we go to at least a meeting a day. If you get yourself to at least a meeting a day, most likely you’re going to stay sober each day, because it holds you accountable.”

— 37-year-old Latinx man with dual diagnoses,
Riverside County

Telehealth use surged during the pandemic, including in behavioral health. Some people with dual diagnosis reported that they have been attending peer support groups online and find them useful in maintaining sobriety. However, others said they choose not to participate. One person with dual diagnoses stated that if a meeting is happening on the web conferencing platform Zoom, “It is not a meeting.”

Social Determinants of Health

People with dual diagnoses were at highest risk of relapse in either condition when faced with the inability to secure employment and/or safe, stable housing. Such critical points of vulnerability often come at transitions such as release from emergency hospitalization, residential treatment, incarceration, or during a mental health or physical health care crisis.

Employment

Finding and keeping a job is often difficult. Most of the interviewees with dual diagnoses want to work, citing not only the need for income and housing security, but also a desire to have a “sense of purpose.” However, they related experiences that showed how difficult it can be for them to get and keep jobs. They may need flexibility in their work schedule to stay in treatment and may have transportation problems. Other barriers include stigma related to homelessness, criminal justice experiences, and mental illness itself.

“When I was working, I never wanted to have to go to my boss to tell him I have to take time off to go get treatment. So usually I would just keep not treating it, and it would just get worse and worse until I got fired or quit. It’s like I would rather get fired for some other miscellaneous bull than have to tell my boss, ‘I struggle from addiction and I’m a major depressive bipolar. So, I need to take off three weeks for my mental health.’”

— 35-year-old White man with dual diagnoses, Riverside

All these problems were represented in the interviews. One mother of a person with dual diagnoses explained that her son sometimes does not think logically when he is in crisis and therefore acts out, leading him once to break a window while working at a fast-food restaurant and being fired. Several participants with a diagnosis of schizophrenia described the “impossibility” of maintaining a job.

A number of interview participants reported that being unemployed led to feelings of depression and anxiety, homelessness, and sometimes to crime. Some said that depression reduced their motivation to seek a job. In addition, pandemic restrictions exacerbated the challenge of finding jobs, and a few people with dual diagnoses lost their jobs due to the pandemic.

“The only thing that I would change is somehow to help people get jobs better. I don’t feel like they meet those needs. They gave me lists of places, but I’ve called a lot of places and they won’t hire. So I feel like they should have more direct help to work with companies to actually make a system where they hire people like me.”

— 37-year-old Latinx man with dual diagnoses, Riverside

Few resources for help in the search for employment. Most participants struggling to find employment did not report having access to resources to support their search. However, some said they received help from providers and/or supportive housing environments with connections to employment or job-training programs.

Housing

Homelessness can exacerbate symptoms and relapses. Many of the interviewees have experienced homelessness, and some were currently residing in shelters. Some described how homelessness aggravated their mental illness and SUD, and how their co-occurring disorders made it difficult for them to find and maintain stable housing. Several people said that being homeless caused feelings of depression and anxiety and led them to use drugs in an effort to feel better. Interviewees also said that being homeless impeded access to health care.

“If there was just some way to give housing to the homeless, to get us off the street, that would be the most necessary thing to getting us to stop using drugs and drinking. I would truthfully like to change my life around and get a home and be able to have my children back in my life. And I’m sure that’s what every homeless person wants for themselves, to be part of the community instead of being labeled homeless.”

— 34-year-old White woman with dual diagnoses, Chico

“Every Tuesday, they have a roundtable meeting where all my counselors, my probation staff, the judge, my lawyer, any of the other staff that helps out and volunteers all get together and they discuss our cases. They go over my weekly report, if I have any concerns or triggers or red flags. They go over what needs to be done for the next week. I feel like that’s a very positive program. I feel like that’s what everybody deserves and needs.”

— 37-year-old Latinx man with dual diagnoses, participating in a court-ordered 18-month outpatient SUD program, Riverside

Some said the constant danger of violence on the streets and being surrounded by others struggling with similar issues made it difficult to maintain their recovery efforts. An SUD provider administrator in Monterey said, “A lot of people use substances just to deal with the stress and the trauma of homelessness. They may take amphetamines to stay awake at night because they’re afraid of being killed, so they can’t fall asleep at night.”

A mother whose son has a dual diagnosis noted that while homelessness is dangerous, living without any support is also dangerous: “He’ll bring street people back to his apartment that rob him and assault him and so — even if he has his own place — it doesn’t mean that he’s safe.”

“Homelessness stuck me in a rut. There wasn’t a day that I would let myself be sober on the streets because it’s such a demoralizing, hopeless, fearful experience. You’d have to walk around with a backpack with all of your belongings, embarrassed that someone might see you. It’s an ugly experience.”

“So I made a promise that I would never be sober or in my right mind when all this was happening. Otherwise I would lose control. I was in no condition to do anything positive whatsoever, so I tried to self-destruct.”

— 39-year-old White man with dual diagnoses, Santa Ana

Supportive housing helps. Many interviewees were living or have lived in supportive housing or “sober living” housing.¹¹ **Supportive housing** combines permanent housing with wraparound care and case management services, while sober living housing offers drug- and alcohol-free housing as well as peer support and addiction recovery services.¹² Those who had previously experienced homelessness expressed gratitude for a place to sleep, shower, and eat. Interviewees also appreciated the benefits from peer support groups, transportation to appointments, and access to counselors or therapists, although some said needed services were lacking.

Not everyone can find a place in supportive housing. Some loved ones of people with dual diagnoses said there were barriers to gaining entry into supportive housing due to the limited number of spaces available and restrictive “one strike and you’re out” rules around using drugs.

“People shouldn’t be just turned away [from housing] because they also do drugs. That means they probably need more help because they’re about to hit rock bottom. Your option shouldn’t be either become a functioning addict or hit rock bottom because you don’t know how to help yourself.”

— Sister of a person with dual diagnoses

To help fill the gap, some mental health and SUD providers said they offer referrals or help people find a place to stay, such as motels, shelters, or transitional housing programs. Some provide transportation support, which can be crucial for people with dual diagnoses. Other providers try to make it easier for people who are homeless to get care. One provider organization that serves mainly people with dual diagnoses made changes to its specialty buprenorphine clinic to better serve people experiencing homelessness. To become a “low-barrier” setting, the clinic added drop-in hours available every day.

Criminal Justice Involvement

Problems accessing comprehensive care while incarcerated are common. Many people said they received some treatment while incarcerated, but there was widespread sentiment among people interviewed that treatment programs relied mainly on providing psychiatric medications rather than therapy and counseling.

“They were giving me treatment in prison, but it wasn’t really hands-on. The therapists were more willing just to give you drugs to calm you down and make you sleep instead of really helping you or talking to you and asking questions.”

— 51-year-old White man with dual diagnoses, Riverside

Some interviewees did see therapists and counselors or attend peer support groups while they were incarcerated. Typically, interviewees said they received treatment either for their mental illness or for their SUD, but not both. In fact, some said their providers did not know about their other diagnosis.

Providers shed more light on some reasons why people with a dual diagnosis who are incarcerated may not receive all of the care they need. Some pointed to narrow contracts between behavioral health providers and state prisons. For example, some contracts allow only cognitive behavioral therapy, and several providers mentioned an inability to offer medication-assisted treatment for opioid use disorder in the prison system. It should be noted that in early 2020, the California Department of Corrections and Rehabilitation and California Correctional Health Care Services launched the Integrated Substance Use Disorder Treatment program.¹³ The program includes the prescribing of MAT when appropriate. All 35 California prisons now include people who are incarcerated and actively on MAT — a total of 11,227 people, up from 546 in January 2020.¹⁴

“Without a supportive family, having a case manager helps me a lot. It makes me feel secure, like I have someone that cares when I get unstable, when I stop taking my meds. They’re here to give support. And I didn’t have that all those years of homelessness and before. I have it now and I believe that’s what helped make me be able to maintain a place to live.”

— 60-year-old Black woman with dual diagnoses, Menifee

Diversion programs offer important benefits. A number of interviewees had been, or were still in, diversion programs, which can allow people to avoid incarceration. Such programs typically require treatment regimens and impose restrictions surrounding many aspects of life. The people with dual diagnoses who had been in these programs typically appreciated the opportunity to invest time and energy in their recovery, as well as to avoid incarceration.

“Basically, if I’m imprisoned, I’m locked in behind bars like an animal, and they’re not treating what’s causing the behavior.

“This [diversion program], to me, offers a way to address my criminal ways, my mental health, and why I’m making those decisions. It gives me tools to think and not do it. It gives me a lot of knowledge about why I’m doing drugs to numb those feelings and not feel so out of place or weird. There’s no advancement like that in prison. That is the difference I see.”

— 39-year-old White man with dual diagnoses, Santa Ana

Court-ordered programs are less effective if people are not ready. People with dual diagnoses with diversion program experience said they were less interested in treatment when they had no choice and the services were imposed on them. Some reported that they only participated in diversion programs because it was required and that they did not want to go to jail. One person described how they would get high before treatment appointments or meetings with their parole officer and would take detoxification concoctions from “head shops” to dilute drug test results.

“I didn’t want to be there [in a diversion program] because I was still getting high. I wasn’t trying to get help. I wasn’t expecting to find anything there to help me quit. I was still out of touch with my circumstances and with my disease. The only cares and worries I had were when I was going to get [arrested] again because then I wouldn’t be able to get the drugs. I was so wrapped up in my own enslaved world of being high.”

— 64-year-old White man with dual diagnoses, Riverside

Release from incarceration presents challenges.

After release, people may have difficulty obtaining health care coverage, continuing any treatment they had been receiving in prison, or connecting to community resources. One person with a dual diagnosis said she was released from jail without an adequate amount of medication. She had been given a 14-day supply of antidepressants with no refills and the review application process for Medi-Cal took 30 days, so she was forced to abruptly stop taking her antidepressants. Providers stressed the need for greater coordination between the criminal justice and behavioral health systems at the time of release because this is period when people with dual diagnoses may be at highest risk for relapse.

Law enforcement officers are often not trained to properly respond to people with dual diagnoses.

Loved ones of people with dual diagnoses spoke about the painful decisions they often had to make, including calling the police during crises. They noted that police officers generally could not provide meaningful help, and instead would arrest their loved ones and/or put them on a 5150 hold. The mother of a person with a dual diagnosis observed that if police officers don't think that somebody has a plan for immediately killing themselves, "they don't help them. And that's insane. So there needs to be more training across the board for hospitals and police."

However, several participants said they have often sought and received support from police officers to de-escalate situations, locate missing loved ones, and educate others on mental illness.

Child custody is a major factor for mothers seeking treatment.

Involvement by Child Protective Services came up in discussions with a number of interviewees. Some mothers described their fear of telling their health care providers about their substance use, or the extent of their problems with mental illness — even when pregnant — out of fear of losing custody of their child or children. On the other hand, some described how their motivation to maintain, or to regain custody of their children, convinced them to seek treatment.

"After I had my second child, I was so upset about the fact that I had used during my pregnancy, that I did quit on my own. I moved somewhere I shouldn't have. I moved up by my mom. My mom is a user... she created a lot of problems for me. I was calling [Child Protective Services] because I was upset about my son. I was being weird, I guess. So I got involved with CPS and then they were the ones that prompted the drug rehab programs."

— 43-year-old White woman with dual diagnoses, Olivehurst

Family members and close friends face challenges.

Some of the caregiver interviewees detailed their struggles with becoming a [Lanterman-Petris-Short](#)¹⁵ (LPS) conservator, understanding their rights as a conservator, or gaining health care power of attorney. Others, who had gained conservatorship, noted that law enforcement personnel and health care providers often do not fully understand or comply with LPS conservatorship rights, including the right to authorize the placement of their loved one in a county treatment facility or hospital.¹⁶ One mother described a situation in which her son was having a psychotic breakdown, and she urged doctors to place him in inpatient mental health treatment. The doctors ignored her request, insisted that his symptoms were due to his drug use, and recommended that he instead be placed in residential SUD treatment.

Another parent attributed some of the challenges they experienced as a conservator to the complexity of the health care system and policies that require adult patients to sign HIPAA (Health Insurance Portability and Accountability Act) agreements before family members or close friends can receive conservatorship. This parent said they developed a local conservator assistance group to support people serving in this role to understand their rights.

“There’s a huge systemic issue, at least in Los Angeles County, where they [doctors] don’t understand Welfare and Institutions Code 5008.2. They’re mandated by law to take family input which would be relevant and recent history into account when making any kind of decision on whether to put someone on a 5150 hold, or whether to keep someone on a 5150 hold and keep them hospitalized. And they’re not following the law at all. Which means that a lot of people like my son are not getting in the hospital even when he tells them that he’s out of control and thinks he might end up dead because he might overdose or walk in front of a bus.”

— Mother of a person with dual diagnoses

Several interview participants cited the National Alliance on Mental Illness (NAMI) as a support resource for themselves and their loved ones with dual diagnoses. NAMI and its state organizations offer resources, education programs, and support groups (both in-person and virtual) for families, individuals, and educators. A parent noted that their involvement with NAMI helped connect them to others who could relate to their experiences.

Interpersonal Relationships and Stigma

Engaging family and friends can support recovery. Many people with dual diagnoses described the support of family and friends as important to their recovery efforts, and a few people believed that not having their loved ones’ support served as a challenge in their recovery.

However, some people described turning away from their families and friends when they were suffering most from symptoms or after getting into trouble. Some reported feeling judgment from loved ones who assume that they will relapse. A mother said that family members did not want to be around her son, and acknowledged her personal shame surrounding his dual diagnoses. She said, “Do I talk about it to people? No, I’m as private as I can be with our family.”

“They still have that uncomfortableness, like, ‘Okay, well, he’s clean now, but when is he going to relapse again? He’s done it over and over so many times.’

“To me, they’re still waiting for me to fail again.”

— 37-year-old Latinx man with dual diagnoses, Riverside

Providers who “really care” make a difference. Interviewees described higher-quality care and better outcomes when they felt like their providers listened, made them feel important, and made an effort to tailor treatment to their individual needs. In several interviews, participants said they were being treated as a “whole person” and expressed gratitude for providers who went out of their way to help them address social issues such as housing, food, or transportation. One person said they felt like their therapists and counselors helped them “find themselves” and motivated them to move forward.

“I have a really supportive family. I even have aunts and uncles that are in recovery with like 30, 40 years’ sobriety and abstinence from drugs. So that is comfortable, and my family knows where I am, and we’re really close.”

— 51-year-old White woman with dual diagnoses,
San Mateo

A person with a dual diagnosis described his positive experience in a men’s rehab program, where they offered more individual sessions with counselors than previous programs he experienced. He said the attention made him feel like counselors were concerned with him and wanted him to get the proper help. Another person said they were grateful when providers checked in via phone frequently and showed patience when describing a new medication and its side effects. Some people with dual diagnoses felt like they could connect on a personal level with their provider due to their similar backgrounds or lived experiences. One explained why his therapist made him feel comfortable: “I mean, we’re just kind of on the same level, and then we’ve been through some of the same stuff.”

“The counselors knew what they were talking about, because they’ve been through the same things that I’ve been through. And they were more caring, you know? More one-on-ones with them. Like times when we were going through struggles.”

— 51-year-old White man with dual diagnoses,
Riverside

Peer support groups offer a safe space. People with dual diagnoses described positive experiences sharing their stories with peer support groups for both SUD and mental illness, particularly when support group leaders had similar experiences. Many people said they have attended peer support groups at their providers’ organizations, supportive housing environments, or through AA or NA. A few described peer support groups as “safe spaces” to be open about their experiences without feeling judged.

“Even though I can’t say they’re my friends, and I don’t know them personally, I know they’re going through the same kind of crap that I’m going through. Not all of them are living in their cars, but they’re all going through hell. And I can be honest and open and talk and not be judged by these people at all, which is nice. It’s a peer network.”

— 56-year-old White man with dual diagnoses,
Los Angeles

Several interviewees said they served as formal or informal leaders or mentors for their peer support group or network. Some people with dual diagnoses and providers noted that facilitating peer support groups, being involved in decisionmaking, and volunteering on advisory boards allow people to serve as role models and to motivate change while also having a sense of purpose.

“Being a volunteer has helped me. It’s been positive . . . just to be able to share my own experiences and try to do better with other people who I know have gone through some of the same stuff. I try to call and check in and see how everything is going so I can give them coping skills.”

— 34-year-old Black man with dual diagnoses, Gardena (Los Angeles County)

People with dual diagnoses sometimes feel stigmatized by their providers. Some interviewees felt their providers judged them or had preconceived notions about them, leading a few to question how honest they should be with those in the health care system. One person described how she was trying to stop using drugs while pregnant, but was too afraid to talk to her obstetrician about it. Several people and their loved ones said the stigma sensed from emergency room (ER) and hospital providers led them to avoid treating withdrawal symptoms or other physical problems. One person described being discharged from the hospital in spite of telling doctors they felt sick; the person’s sepsis was treated only after readmission for an overdose.

People described different ways they felt they were treated with disrespect or didn’t get sufficient attention and support from providers. One man said he felt like the doctors at a drug treatment program were not seeing him as a “whole person” and were just focusing on his criminal history and drug use.

Other interview participants felt they could not connect with their providers. For instance, one person described their case manager as “too clinical” and felt like all their interactions were like an interview rather than a conversation. Another person described his mental health therapist by saying, “He’s just too stern. He didn’t get what I was saying and where I was coming from.”

“So you have to wait another three weeks, and then you finally see the doctor. And then the doctor just listens to what you say your symptoms are and he just prescribes you medication. It’s not really therapy. It’s just, ‘Here, take this pill and go away.’ It didn’t really make me feel all that good. It didn’t make me feel like I even mattered. It kind of made me feel like I was just another number.”

— 34-year-old Latinx woman with dual diagnoses, Hemet (Riverside County)

A dual diagnosis carries more stigma than SUD or mental illness alone. People interviewed described an almost overwhelming feeling of embarrassment or shame due to having two diagnoses, both of which are stigmatized in society. While many were more accepting of their primary, or original, diagnosis, the second diagnosis not only made it more difficult to obtain treatment for both conditions but also increased their perceived stigma. One interviewee described what he typically heard from others in treatment: “They say, ‘Well, I have a mental health problem, but I’m not a junkie.’ I was like, ‘Well, I have substance abuse, but I’m not mental. I’m not crazy.’”

“My grandmother used to say, ‘We have no mental illness in our family,’ and yet my uncle and my aunt were both horrible alcoholics. I think depression was very prevalent in our family. I think every family probably has something to do with mental illness. I don’t think anybody’s untouched. I mean, what’s normal? But people don’t like to talk about it.”

— Loved one of a person with dual diagnoses

Many participants perceived that others in their life believe SUD is a sign of weakness and felt shame that they did not have the “willpower” to stop using. Several people with dual diagnoses described how stigma stemmed from a lack of understanding that a mental health condition could impact substance use or vice versa. One person said his family could not understand why he took prescription medication for a mental health condition, “which they view as drug seeking.” Some said they retreated from family and friends as their substance use and mental health issues worsened.

“There was despair because I felt bad being there. Always in my mind was, ‘What are people going to say? What will people say?’ And ‘My family will say that I am crazy.’”

— 55-year-old Latinx male with dual diagnoses, Los Angeles

One interviewee described how she was able to normalize her treatment for a mental health condition by separating it from her SUD. She observed, “The truth is, a lot of people who don’t consume or use drugs also have a mental health diagnosis. If you don’t treat it, it can become a bigger issue.”

Fear of stigmatization can lessen over time. A number of older interview participants (age 49 to 60) who were diagnosed long ago became emotional when describing their journeys and how they overcame stigma from families and providers. One man delayed seeking care for fear the diagnosis would be on his “record” and prevent him from getting jobs. However, “it got so bad” that his health concerns outweighed the stigma.

Others said their feelings of shame or embarrassment dissipated over time, in part due to meeting other people through group therapy who were going through similar experiences. They described currently feeling support from family in addressing their dual diagnosis, and that they all came to a place, over time, of not “worrying too much about what people think.” When talking about stigma, one person mentioned “fighting stigma” or “bringing awareness to the community” as a way of confronting this feeling. Many interviewees indicated they had family members who struggled with mental illness or substance use.

“As soon as they know he’s got an addiction, they don’t treat the physical problems. A lot of times he has had such physical damage because of the not eating for days and getting beat up on the street and having infection issues. They totally disregard it because they just chalk it all up to being an addict. And they don’t really pay attention to why the combination of addiction and bipolar is so life-threatening.”

— Loved one of a person with dual diagnoses

Race/Ethnicity

The five people with dual diagnoses who were interviewed in Spanish had distinct fears about seeking treatment. In this study, those interviewed in Spanish lived in urban areas with a high proportion of Latinx residents. All these interviewees reported being able to access either a provider who spoke Spanish or a Spanish interpreter. One person with a dual diagnosis said some providers would ask about immigration status, and that would deter her from getting treatment. This interviewee, and other people with dual diagnoses who were undocumented, expressed fear that accessing care would negatively impact their path to citizenship. (See Appendix B for limitations in recruiting Spanish-speaking participants with limited English proficiency.)

Some people felt stigma was especially pronounced in their own racial and ethnic groups. A number of Black interviewees described beliefs ingrained in their families and communities that made it difficult to accept their diagnoses and seek care. One person explained how growing up in a Black family taught her that “if you have a problem, you don’t take it out of the house.” A few people described their own experiences denying their mental illness as a result of the stigmatization of mental health treatment among the Black community.

Several people with Latinx backgrounds described their experiences feeling like it “wasn’t okay to have those kinds of [mental health] issues.” One said that they grew up thinking they needed to “man up and deal with things” and expressed worry that their family would think they were crazy. Providers and subject matter experts noted how cultural norms lead some Latinx people to deny they need treatment, specifically medications, because “they can do it by themselves.” The providers and subject matter experts also believed that stigma around mental health disorders and SUD in Latinx communities prevents people from seeking care.

“I never got help. Being African American, at least in our family, you don’t talk to therapists. If you have a problem, you don’t take it out of the house. My mom drank, so I knew not to go and tell anyone that. I was taught early on that you just don’t tell anyone your business. So when I would talk to a therapist, I wouldn’t tell them anything.”

— 45-year-old Black woman with dual diagnoses, San Mateo

Race/ethnicity can make people feel isolated during treatment. Several Black people with dual diagnoses felt that they “stood out” in majority-White treatment settings and that others did not understand their life experiences. One person described what it was like when they first started seeking treatment: “I used to feel like everywhere I went, I was the only Black girl. No one ever understood, couldn’t understand, what I was saying, and then they were trying too hard to understand it.”

One Black male interviewee said he left SUD treatment following an experience where he faced racism from fellow patients, and staff did not address it. Another Black interviewee described needing different hair supplies than the White patients in a residential treatment center, but restrictions made the products unavailable to her. She believed this impacted her feelings of comfort and inclusion in treatment.

Several interviewees described their preference for receiving treatment from providers of the same racial and ethnic background because these providers can relate to them and help them feel more comfortable. One interviewee noted, “My therapist was raised in the same kind of environment that I lived in. Usually when I pick therapists, almost like a doctor, I think of a White lady or an old White man — someone that you

can't even relate to, with some glasses on their nose. But mine, she dresses like I would dress. She's like a regular person."

One therapist also described challenges establishing trust with a Native American client, noting that the client expressed hesitancy that they were receiving care from someone outside of the providers with shared background they had seen in the past through Indian Health Services.

Despite All the Challenges, Most Are Improving

Although interviews with people with dual diagnoses and their loved ones highlight difficulties, they also revealed successes in seeking and receiving treatment. Their stories make real the impact of structural and cultural problems that complicate and sometimes derail their progress toward health. And they show that coordinated, quality care makes the difference.

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During the interviews, people with dual diagnoses were asked if they believed they were improving in their path toward health. Most said yes. Only one person said they did not feel they were improving, while a few reported they were not "actively getting better."

Of those who said they were improving, several reported that they "feel good" and are able to open up more to friends and family, and generally feel less stress and anxiety. A few said they are experiencing fewer symptoms such as relapses, overdoses, and urges to use substances. Some said they think they are improving simply because they are engaged in treatment. One described being able to now help others and give back to the community. Another reported having a better understanding of where trauma comes from and how influential trauma is to addiction.

Some interviewees spoke about what they had learned through treatment and their determination to proceed toward wellness. A 51-year-old White female in San Mateo explained:

"It was a learned behavior that I acquired from the trauma that I have gone through in my life. This place [residential drug treatment program for women] made me see things that now make sense. And it's coming together like a puzzle that's been just pieces scattered all over the universe. And now, I'm finally knowing that it's not my fault or that I'm different or I'm like an alien or a weirdo or just a psychotic, crazy woman.

"No wonder. What I've been through is horrific, and I've been taught to just not ever talk about that. That's not okay. And it's not even my family's fault. That was just the only thing that they knew, and that's how I learned that.

"So I'm here to break the cycle for my daughter and then her children and their children."

Another interviewee with a dual diagnosis said simply, *"I'm enjoying sobriety."*

Conclusion — Moving Toward Integrated Care

The 93 interviews conducted for this report revealed important information about the experiences of people with dual diagnoses in seeking and receiving care, and that of their families and friends. Many of these firsthand stories reflect the pervasive problems that hinder access to coordinated care for both diagnoses. The systemic dysfunction that segregates mental health, substance use disorder, and physical health care into separate administrative and financial systems is cumbersome for providers and organizations to work with. But for the people who need effective care and need it quickly, the impact can be devastating.

The interviews made clear the power of the “primary diagnosis” to corral people into either the mental health silo or the SUD silo and to effectively keep them there in the long term. Providers are frequently prevented from treating or billing for a “secondary” diagnosis, and cannot easily coordinate care across systems. People in residential treatment for either mental illness or SUD often find that their other diagnosis is ignored, putting them at risk of relapse. Common difficulties in access include long wait times, medication shortages, lengthy paperwork, and limited availability of providers — which erode the motivation of people to seek and sustain care.

All interviewees — people with dual diagnoses, their loved ones, provider administrators, direct care providers, and subject matter experts — agreed that integrated care is the best way to improve outcomes. Ideally, integrated care would involve the concurrent treatment of substance use and mental illness in the same location by a multidisciplinary team, supported by a single payment and data system. When fully integrated care in the same location is not feasible, it is still possible to support robust and consistent communication between providers. Many of the people interviewed attested to receiving effective care due to careful coordination among their mental health and SUD providers.

All interviewees — people with dual diagnoses, their loved ones, provider administrators, direct care providers, and subject matter experts — agreed that integrated care is the best way to improve outcomes.

Coordination with other systems, including those that address the social determinants of health, is a critical factor in improving outcomes. Many people with dual diagnoses emphasized that they achieved well-being when all their health care providers worked together, and when other supports were available to them: housing, employment training and placement, and transition from residential treatment or incarceration.

Overall, the interviews underscored the importance of an integrated approach to treatment that addresses people’s mental health and SUD diagnoses, as well as their basic human needs for shelter, income, social connections, and respect. As several interviewees expressed, they respond best when they perceive they are being treated as a “whole person.”

Appendix A. How Structural Separation of Mental Illness and SUD Treatment Confounds Provider Organizations and Providers

The separation of mental illness and SUD treatment frustrates provider organizations and clinicians in their attempts to treat people with dual diagnoses. Following are some examples and quotes from provider administrators and direct care providers who were interviewed for this report. Quotes have been lightly edited for length and clarity.

Separate funding streams and contract structures present challenges. There are different requirements and contracting schedules for mental health treatment and SUD. A behavioral health director in San Bernardino County described how the rules can conflict with the reality of patient care.

“I can’t start billing until I have a diagnostic code. And it can’t be a provisional code . . . so I have to figure out what is wrong with you right now, and give you a label, and then I have to put together a treatment plan for that diagnosis. We all know that’s not how real life works, but that’s how we’re kind of forced to do it. Sometimes we’ll have someone present and they’re psychotic, but we don’t know what’s causing the psychosis. Is it a psychotic disorder or is it methamphetamine use? So we need time for that to clear up a little bit. Right now I can’t see anyone who doesn’t have a truly identified mental health diagnosis on our mental health side. I can only see you on the SUD side — if they have that.”

Direct care providers gave examples of how they tried to find ways to fully treat patients despite the rules. An addiction psychiatrist in Los Angeles County offered this example:

“In our full-service partnership, we had groups to help treat mental illness, to treat grieving, to treat depression. We could get patients dialectical behavioral therapy, but we were not authorized to have any substance use treatment groups on our site. We had a counselor who does kind of individual therapy, but she had a background in substance use disorders,

and she was kind of doing it almost like surreptitiously. She’s not allowed to say she’s doing substance abuse treatment, but because she was so good at what she does and good at working with these clients, she was able to engage them and address these issues in a roundabout way.”

Differing guidelines for treating mental illness and SUD can lead to inappropriate or incomplete care.

Multiple subject matter experts, providers, and provider administrators discussed restrictions related to billing and reimbursement. They must assign a primary diagnosis code to enroll a person into treatment and to file a claim for payment, placing the person in one system or the other rather than treating both issues at the same time. Providers are prevented from administering multiple services on the same day in the same location, a restriction that can be harmful for people with dual diagnoses seeking care for both conditions. Many direct care providers discussed using outside organizations such as sober living facilities and community resources as well as other creative solutions to the segmented regulations. The director of an integrated health program in the Bay Area gave the following example:

“If you have a contract to provide SUD treatment in a county, and if some of your clients have a co-occurring serious mental illness, you may not be able to provide those services even though you have the capacity and the ability and you do it in other places. If you don’t have a contract to do that in that county, then if you have a client who has a bipolar disorder in addition to their substance use, you may have to refer them out for psychiatry because it’s not covered under the substance use contract. It’s just a silly barrier to care.”

Much documentation is required to provide and be reimbursed for mental health and substance use care. In addition to maintaining separate EHR systems, providers must also meet requirements for reimbursement by Medi-Cal. Some provider administrators and direct care providers described the requirements as time-consuming and counterproductive to providing care. The director of an integrated health program in the Bay Area said:

“Every progress note is a narrative documentation that must be tied back to a problem area in the treatment plan. So if you have a client who is coming to you for SUD issues but their grandmother died and they’re full of grief and sadness, if grief isn’t in the treatment plan and you document discussing grief in a session, then you could potentially have service disallowed, which is ridiculous.”

Agencies wanting to increase their capacity to fully treat mental illness and SUD need statewide credentials. The requirements for getting these credentials are separate (substance use is a state-level license while mental health is county-level). The process can be long, and providers must pay fees throughout the credentialing process. A former managing director of a residential drug treatment program said:

“Getting credentials in California right now even to get drug Medi-Cal certified is taking 18 to 24 months . . . agencies are wringing their hands because the delays in actually going through any certification process in the state right now are — it’s just not even practical.”

Appendix B. Demographics of All Interviewees

As briefly described in the introduction, in summer 2020 NORC conducted 93 semi-structured hour-long phone interviews with people with dual diagnoses, family and close friends of people with dual diagnoses, direct care providers, subject matter experts, and provider administrators. Interview participants received a \$50 gift card to thank them for their participation. (See Table B1.)

Table B1. Number of Interviews, by Interview Type

INTERVIEW TYPE	NUMBER OF INTERVIEWS
People with Dual Diagnoses	54
Family Members / Close Friends of People with Dual Diagnoses	8
Direct Care Providers	20
Subject Matter Experts	6
Provider Administrators	5
Total	93

Fifty-four people with dual diagnoses were interviewed. Forty-nine were interviewed in English, and five were interviewed in Spanish. The most commonly reported mental health diagnosis was depression, and the most commonly cited substance used was alcohol. (See Table B2.)

Table B2. Mental Health Diagnosis and Type of Substance Used by Client

	PERCENTAGE (n)
Mental Health Diagnosis	
Depression	55% (29)
Bipolar Disorder	23% (12)
Anxiety	13% (7)
Schizophrenia	9% (5)
Post-Traumatic Stress Disorder	9% (5)
Unspecified	8% (4)
Schizoaffective Disorders	6% (3)
Paranoia	6% (3)
ADHD	4% (2)
Hearing Voices	4% (2)
Substance	
Alcohol	47% (25)
Methamphetamines	30% (16)
General*	13% (7)
Heroin	11% (6)
Cocaine	8% (4)
Unspecified	6% (3)
Other Opiates	4% (2)
Spice	2% (1)

*Seven people did not cite a specific substance but described a general history with substance use or issues with drugs and alcohol.

Note: Participants cited multiple mental health diagnoses and substances, so number (n) does not add up to 54 in either table.

The substance use findings are in line with general trends in drug use in California. In 2018, the opioid-involved overdose death rate per 100,000 people was under 6.2 in California.¹⁷ Methamphetamine use in California has seen periods of increase in the past 20 years, notably between 2000 and 2006.¹⁸ This is pertinent to people in our study, as many had long histories of drug use extending back to 2006 and before. Additionally, California saw another sharp increase in methamphetamine use in 2019.¹⁹ These waves of methamphetamine popularity across the state could explain the high prevalence of methamphetamine use among the study population.

Spanish-Speaking Participation Limitations

Though significant effort was made to recruit and interview a study sample that represented a diversity of Californians with dual diagnoses, the study team faced some challenges in achieving this goal. The team set out to interview 10 Spanish-speaking people with limited English proficiency but were able to interview only five. The initial recruiting approach consisted of following up with direct care providers who noted they served a Spanish-speaking population to share the recruitment flier in Spanish. County websites were reviewed to identify Spanish-speaking providers, and Latinx mental health and SUD organizations across the state were identified and asked to share the Spanish-language recruitment flier with their clients. NORC also partnered with a Spanish-language survey panel to assist in the recruitment of Spanish-speaking people with dual diagnoses.

Based on the literature, feedback from providers who treat Latinx populations, the conversations with Latinx people that were conducted, as well as anecdotal evidence from concurrent NORC projects, a number of hypotheses were considered for why more interviews were unable to be completed in Spanish. Primarily, that the political environment and discussions of public charge in Latinx communities in California dissuades Spanish-speaking people who are undocumented or who are pursuing a path to citizenship from participating in research studies like this one. Additionally, some interviewees mentioned stigma in Latinx cultures, which may lead people to avoid defining themselves

as someone with a dual diagnosis, or to avoid care — in either situation, the recruitment strategy used would have missed them. Finally, some providers said that some people who might speak Spanish at home find it easier to speak in English while receiving health care since there are not always direct Spanish translations for terms commonly used when describing county-level behavioral health care services.

Nine family members or close friends were also interviewed to gain additional perspective on the experiences of people with dual diagnoses as well as to better understand the experiences of those who support people with dual diagnoses. (See Table B3.)

Table B3. Relationship of Family Member or Close Friend to Individual with Dual Diagnosis

	NUMBER
Mother	5
Sister	2
Father	1
Close Friend	1
Total	9

Finally, five provider administrators and five subject matter experts were interviewed, along with 20 direct care providers. (See Table B4 for provider focus area.)

Table B4. Provider Focus Area

	NUMBER OF INTERVIEWS
Mental Health	12
SUD	4
SUD / Mental Health	3
Neither (ER provider)	1

Endnotes

1. Providers, administrators, and experts included 12 specialty mental health providers, four SUD providers, three SUD / mental health providers, and one emergency room provider. All served Medi-Cal enrollees.
2. For background on system challenges and potential solutions, see Logan Kelly, Allison Hamblin, and Stephen Kaplan, *Behavioral Health Integration in Medi-Cal: A Blueprint for California*, California Health Care Foundation (CHCF), February 2019.
3. For information on federal poverty level, see “2021 Poverty Guidelines,” US Dept. of Health and Human Services, January 26, 2021.
4. Extensive efforts were made by the researchers to recruit at least 10 Spanish-speaking interviewees; 5 participated in the interviews.
5. Michael S. Spencer et al., “Discrimination and Mental Health-Related Service Use in a National Study of Asian Americans,” *Amer. Journal of Public Health* 100, no. 12 (December 1, 2010): 2410–17.
6. “Substance Abuse Confidentiality Regulations,” Substance Abuse and Mental Health Services Administration (SAMHSA), last updated March 30, 2021.
7. *COVID-19 Public Health Emergency Response and 42 CFR Part 2 Guidance* (PDF), SAMHSA.
8. *CalAIM Explained: A Five-Year Plan to Transform Medi-Cal*, CHCF, July 2021.
9. “Drug Medi-Cal Organized Delivery System,” DHCS, last modified July 8, 2021; and *Program Eligibility and the Drug Medi-Cal Organized Delivery System Frequently Asked Questions* (PDF), DHCS, last updated September 2018.
10. *Drug Medi-Cal Organized Delivery System — Updated Policy on Residential Treatment Limitations*, Behavioral Health Information Notice 21-021, DHCS, May 14, 2021.
11. See “Affordable Housing Models and Recovery,” SAMHSA, January 5, 2021.
12. “Supportive Housing,” US Interagency Council on Homelessness, last updated August 15, 2018.
13. “Integrated Substance Use Disorder Treatment (ISUDT),” California Correctional Health Care Services (CCHCS).
14. “ISUDT Program Overview,” CCHCS, accessed July 15, 2021.
15. *Lanterman-Petris-Short Act*, Welf. & Inst. § 5000.1.
16. “Guide to LPS Conservatorship for Family & Friends,” National Alliance on Mental Illness (NAMI) Westside Los Angeles; and “California Laws,” NAMI Westside Los Angeles.
17. “Opioid Summaries by State” (2018), National Institute on Drug Abuse, April 16, 2020.
18. Paul J. Gruenewald et al., “Mapping the Spread of Methamphetamine Abuse in California from 1995 to 2008,” *Amer. Journal of Public Health* 103, no. 7 (July 1, 2013): 1262–70.
19. “Meth Addiction Trends for California 2020,” California Highlands Vistas.