



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

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 fully coordinated and effective care, causing unnecessary suffering, billions of dollars in health care and social service costs, and poor health outcomes.

The California Health Care Foundation recently [released a new study](#) based on research from NORC at the University of Chicago. It highlights the experiences of Californians with dual diagnoses, the family and friends who support them, as well as providers. The 93 interviews conducted for this report reveal important information about the experiences of people with dual diagnoses.

### Today's fragmented care system is difficult to navigate

Dozens of firsthand stories expose pervasive problems in the health care system, including a care environment that continues to be divided into separate systems — one for mental health treatment and one for substance use disorders, each with its own data and financing mechanisms, charting requirements, and privacy regulations. Physical health care is yet another separate system.

### The effects on patients can be devastating — and last a lifetime

While the siloed care system is cumbersome for providers and patients alike, it also directly contributes to poor health outcomes. The problem begins as soon as people enter treatment and their presenting symptoms are

## Common, but Untreated

**1 in 3 people** (33%) with a substance use disorder has a co-occurring mental health condition

**1 in 5 people** (20%) with a severe mental health disorder will also develop a substance use disorder

**Only 1 in 13 people** (7.4%) with dual diagnoses receives treatment for both conditions

diagnosed, either as mental illness or substance use disorder, but rarely both. The health system's reliance on this either/or "primary diagnosis" determines not only where people enter care but how they self-identify moving forward, putting them at risk of relapse or never having their illnesses fully treated. This fragmented approach to care permeates their experience with the health care system throughout their lives — and also increases their likelihood of experiencing unemployment, incarceration, and homelessness.

### A clear solution: integrated care, addressing all the social determinants of health

The report also highlights what works — coordinated care across mental health, substance use, and physical health systems. Many people with dual diagnoses emphasized that they only 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.

### About the study participants

The researchers identified and interviewed 93 people with in-depth personal or professional knowledge about dual diagnosis:

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

## The Risks of an Untreated Condition

The report highlights the difficulties experienced by people with dual diagnoses and their loved ones. These stories make real the impact of structural and cultural problems that complicate and sometimes derail progress toward health.

### A vicious cycle of homelessness, substance use, and declining mental health



**Shea:** *"This is my home. It's my car. Sleep was hard to come by when I first became homeless. So, I drank every night. I can feel the depression starting to creep in. Once it gets there, it's hell to get out of it."*

### A lifetime of missed chances to get treatment, avoid relapses, and stay out of the justice system



**Desiree:** *"The turning point was when I woke up in jail. I was 50 years old when I was diagnosed. If I had received that type of diagnosis, I could have saved years of not relapsing."*

## The Benefits of Integrated Care

The report also illustrates how integrated care provides a pathway to a better life. People's stories show that coordinated, quality care makes the difference. During the interviews, people with dual diagnoses were asked if they believed they were improving in their path toward health. Most said yes.

### A key step: addressing the social determinants of health



**Ralph:** *"Having a place to live has taken away a big part of why I feel like I use. With stable housing, it's just that whole part of the equation is taken care of."*

### A long-term solution: caring for the whole person



**Rosalind:** *"When you're homeless, and you don't have anywhere to live and you're mentally ill, it's hard to find proper treatment. The breakthrough for me was when I got housing. I was assigned a case manager, a therapist, a psychiatrist, a substance abuse counselor, a team that came together to give me support, and I didn't have that for years. I believe I got the right diagnosis and the right medication."*

To view the full report, please visit:

[In Their Own Words: How Fragmented Care Harms People with Both Mental Illness and Substance Use Disorder](#)

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