Section I

Understanding Substance Use Disorders: Key Issues and Context for Donors

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Section 1: Understanding Substance Use Disorders

INTRODUCTION

Key Issues and Concepts

Substance use disorders (SUDs) exact a heavy toll on individuals, their families, and society at large. An estimated 20 million adolescents and adults in the United States—approximately 1 in 12—suffer from an SUD.[6] In health care costs, crime, incarceration, and lost productivity, SUDs cost the U.S. hundreds of billions of dollars annually; that's more than the costs of smoking and obesity combined.[7] Although SUDs are a significant problem in many countries, this report focuses on the United States.

The following section introduces donors to information and concepts important to understanding opportunities to lower the social and economic burden of SUDs, including:

- What is a substance use disorder?
- What causes them?
- Who has them?
- What kind of harm and negative outcomes do they cause?
- What's the role of stigma, misinformation, and criminal justice?
- Why is this a particularly opportune time for philanthropic investment?

I don't take pain pills for pain. I take them to feel normal. I wish I could remember what it felt like NOT to be on pills! I need help to stop. They used to make me feel good. Now they just keep me from being sick. I'm scared to tell my doc ... I just feel like nobody understands. What should I do from here? Who should I talk to?

– Anonymous user[5]

What is a substance use disorder?

A substance use disorder, in the simplest terms, is **the continued use of drugs or alcohol despite trying to stop and/or causing harm to self or others**. It's a functional definition: does a person's use negatively impact their happiness, relationships, health, or ability to meet their responsibilities—and do they continue to use anyway?[8] Of course, some substances, such as alcohol and prescription drugs, are legal for adults and not problematic in moderation or as prescribed. "Use" crosses into "disorder" when these substances are regularly consumed despite harm to the user and others. (For a full clinical definition, see page i.)

For many people, their disorder is a chronic condition, like Type 2 diabetes or asthma.[9] Relapse is therefore a symptom of the disorder, just like an episode of low blood sugar or an asthma attack. As with other chronic conditions, good care management can reduce or eliminate these symptoms.

What differentiates SUDs from many other disorders is that there is an undeniable behavioral element: someone who chooses never to try drugs or alcohol will not develop the disorder. The complicating factor is that most people who *do* choose to use drugs or alcohol also will not develop the disorder. For some fraction of those people, however, their use will take them down a slippery slope to physiological and psychological dependence: their brains will physically alter to reinforce the cycle of craving and use, and their behavior will follow. While there is evidence for a genetic component, there is no foolproof way to predict who might become addicted. Any number of biological and environmental factors can interact to make someone more vulnerable to the disorder—or to protect them despite risky personal choices.[10]

Finally, while some in the field include tobacco use as an SUD, we have not included it in this report. We focus on substances with mood-altering effects and other negative consequences consistent with the functional definition outlined above.

TAKEAWAY: A substance use disorder (sometimes called addiction or substance abuse) is the continued use of drugs or alcohol despite trying to stop and/or causing harm to self or others. Substance use disorders can include both legal and illegal substances.

What causes SUDS?

The short answer is: we don't really know. Lots of people regularly consume moderate amounts of alcohol or experiment with drugs without developing SUDs. We do know that adolescents are the highest-risk age group for development of SUDs. Adolescence is a crucial period for brain development. During this time, major shifts in development occur in the prefrontal cortex and limbic regions of the brain. These changes are thought to contribute to increased risk-taking and novelty-seeking behaviors, such as engaging in substance use.[11] Along with these brain developments, social influences such as peer pressure are especially pronounced in the adolescent period, further increasing teens' risk of initiating and continuing substance use.[12]

When it comes to understanding why certain adolescents or adults develop SUDs while others do not, we know much less. Studies of identical twins have shown that genetics plays a role, but environmental factors are important as well. For both reasons, having a parent with an SUD increases the likelihood that a child will develop the disorder.[13-15] A 2008 study of national survey data from over 90,000 adolescents found that the strongest risk factors were *individual risk factors* (favorable attitudes toward illegal activities, low perceived risks of drug use, sensation-seeking, rebelliousness, and others) and *peer risk factors* (friends' delinquent behavior, friends' use of drugs, peer rewards for risky behavior, and gang involvement).[16] Having a mental illness such as depression is also a risk factor.[17] But risk factors are simply associated with a higher likelihood of developing an SUD. The *causal* link is unclear.

We also know that once a person develops an SUD, the brain can change in ways that make it even more difficult to stop using. Recent research has shown that SUDs alter brain structure, and scientists are continuing to learn more about what that means. These changes can be one reason why, for many people, recovery isn't just a simple exercise of willpower.

TAKEAWAY: Adolescents are at particular risk for developing SUDs. Certain risk factors such as mental illness, genetic susceptibility, and friends who use can make SUDs more likely. The decision to use or not use before a disorder develops may be a personal choice, but once a person has developed a disorder, that person's brain changes. At that point, stopping use often requires more than a simple exercise of willpower.

Eventually, the little bags weren't enough to stave off the symptoms of withdrawal, and more and more was required just to get me to work, just to get me to sleep, just to get through this trauma, just to not feel how miserable I was … and then that little promise you made to yourself – "never ever a needle" – begins to get broken down … Now the game is in a different league … it's been 17 years this year since I injected my last hit of heroin which most certainly would have been in my neck, the only veins I could use at that point in my addiction.

– Vanessa, 17 years clean[18]

Who are the 1 in 12 Americans suffering from substance use disorder?

Over 20 million adolescents and adults in the United States suffer from an SUD (8.5% of the population over age 12).[20] SUDs affect people from all walks of life and might look different from person to person. Examples might include a recent college graduate who gets drunk every night in order to manage anxiety, a successful professional who is binging on cocaine every weekend, or a rural teen who starts with painkillers and begins injecting heroin when the pills become too expensive. SUDs can be found in all socioeconomic groups, among all races and education levels. More than half of adults with an SUD are employed full-time, and adults of all education levels are equally likely to suffer from alcohol dependence. About one in five young adults ages 18-20 uses illicit drugs, whether or not they're in college full-time.[21]

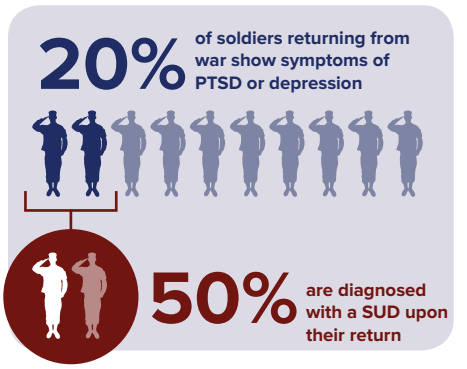
Alcohol is by far the most commonly abused substance. Marijuana use is becoming more common, while cocaine use has decreased.[22] Misuse of prescription medicines has been the fastest growing drug problem; it has been described as an epidemic by multiple agencies such as the FDA, DEA, CDC, and ONDCP. It is a particular issue "among middle class adults, adolescents, and military members and combat veterans who are at risk because of chronic pain."[23] Relatedly, heroin use is rising rapidly as a result of prescription opioid addiction.[24] Evidence has shown that new heroin users often initially abuse prescription opioids before shifting to less-expensive heroin, and the number of heroin users nearly doubled between 2007 and 2013.[25, 26] Regardless of the trends in individual substances, the overall rate of SUDs has remained steady.

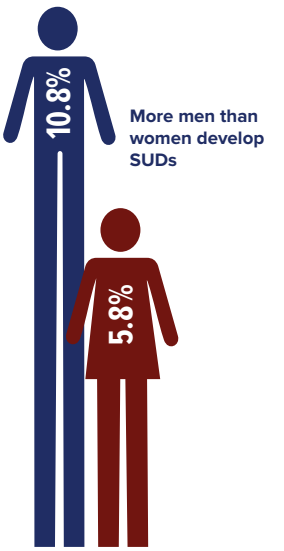
When I was using heroin, very few people were aware of it. I was ranked in the top 4% of my 1,000+ high school class and a member of the varsity basketball team; not the most likely suspect for heroin addiction … I can go for months without being tempted to use, but if something happens to trigger my need, the craving comes back as fresh as it was the very first week of sobriety.

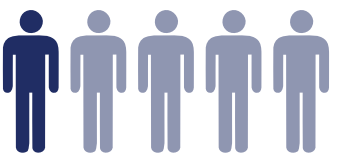
– Jack, former heroin user, nine months clean[19]

TAKEAWAY: People with SUDs are found in all walks of life, from those working steady jobs, to celebrities, to the homeless and unemployed. SUD rates are particularly high among young adults, as well as certain populations, such as those in jail. While alcohol-related SUDs are the most common, SUDs related to painkillers and heroin have been rising.

SUDs are a broad category and might look different from person to person.







About one in five young adults ages 18-20 use illicit drugs, whether or not they're in college full-time.

Adults of all education levels are equally likely to suffer from alcohol dependence.

For sources see page 64.

What kind of pain and damage do SUDs cause?

Those with substance use disorders also face other serious problems, at rates higher than those in the general population. Those problems include:

- Death
- Health conditions including liver failure, HIV/AIDS, and other blood-borne infections such as Hepatitis C
- Homelessness
- Poverty
- Family upheaval
- Repeated incarceration

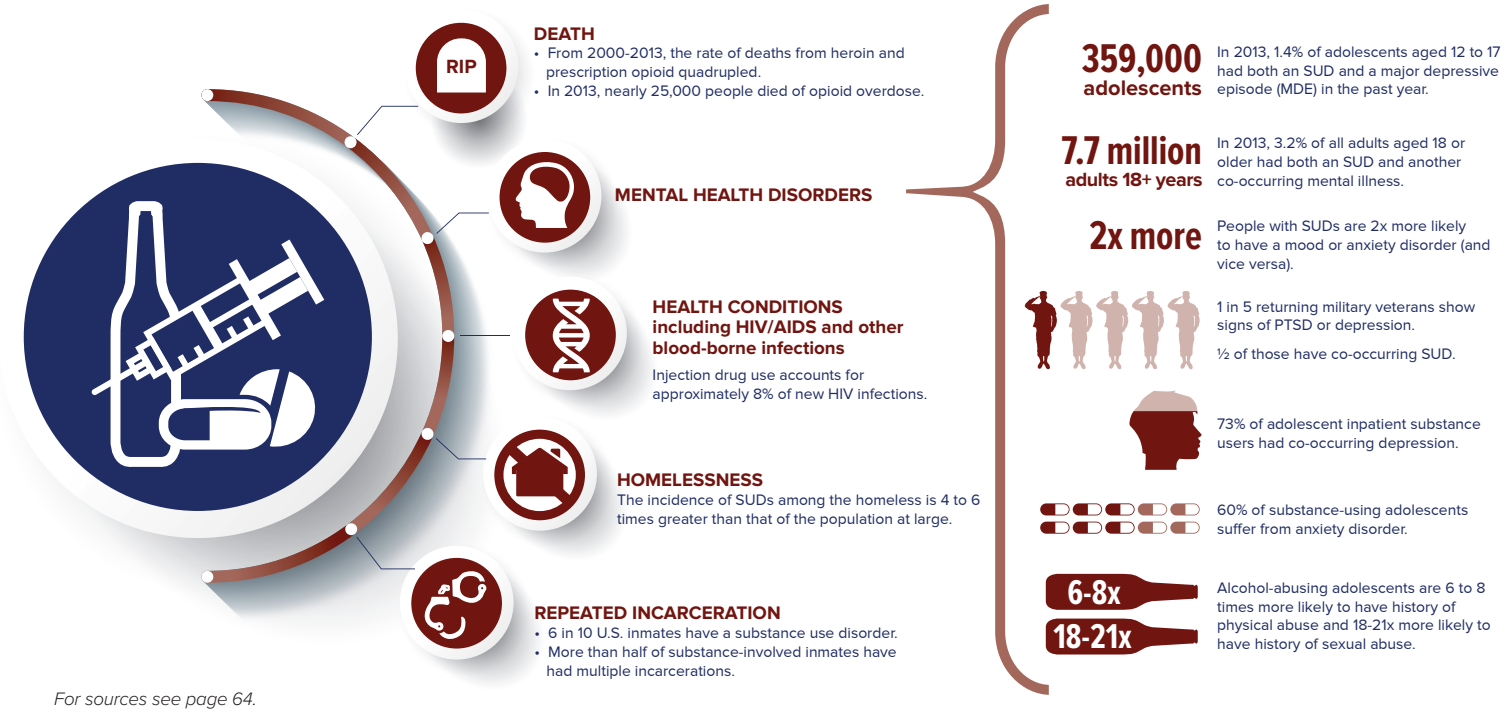
Moreover, individuals with SUDs are not the only people affected. Friends and family suffer as they grapple with their loved one's disorder and its effect on their lives. Damages also occur at the societal level through the spending of public resources, incidence of crime and violence, and the opportunity cost as one-twelfth of the population struggles to function at full capacity. Taxpayers—with or without SUDs—bear that burden, as SUDs are estimated to cost the U.S. over $400 billion in crime, emergency services, and lost productivity costs each year.[27]

TAKEAWAY: People with SUDs suffer in real and acute ways that complicate recovery. The damage and cost of SUDS also extends well beyond individuals with the disorder and includes their families, communities, and society at large.

I am now 35 and for as long as I can remember my father has been injecting heroin. I wonder when I will get the call to identify my father's body ... I have no words of wisdom [to offer], as a 10-year-old boy or a 35-year-old man watching an addict destroy everything he loves for 30 minutes of nirvana. I can only say, that an addict is never alone in their suffering.

– Geoffrey, son of a heroin addict[28]

People with substance use disorders are more likely to experience other illnesses, homelessness, and even death.



For sources see page 64.

Stigma and misinformation

Stigma has a direct role in the damage caused by SUDs. The factors underlying the stigmatization are complicated. For one thing, while many with SUDs manage to continue meeting the demands of daily life, the most visible symptoms of severe SUDs are, in many cases, behaviors that can hurt loved ones, are socially unacceptable, or even illegal: not meeting commitments, neglecting children, risky sexual behavior, and crimes like theft and violence. The disorder is tied in many people's minds with these behaviors. In addition, empathy can be limited by the fact that many people have personal experience with drugs or alcohol but never develop a disorder. It can be difficult to understand why someone else can't stop if you can.

Stigma, lack of information, and stereotypes complicate attempts to make progress. Stigma makes some SUD patients and their families feel ashamed and afraid to seek help, and it can keep a doctor from providing the best care for fear of offending patients by asking about their substance use. The fact that SUDs are a "taboo" subject also means that information that could be helpful flows less freely. Doctors may be unaware of recent research on more effective treatments and may not know where to send patients for help.[30] What's more, unscrupulous and ineffective SUD "treatment" providers can stay in business because when SUD patients and their families don't even acknowledge being in treatment, there is no word of mouth that might help close down a bad provider. Since addiction is a politically unpopular topic, even known life-saving, cost-saving, evidence-based programs are hard to get funded. Finally, stereotypes and misinformation reinforce the idea that addiction is simply a moral failing, averting questions about the role and quality of care providers. For all of those reasons and more, stigma kills.

I feel horrible. I look horrible. I hate myself. I am crying writing this because I just don't know where to go or what to do. Everyone thinks I am so strong but I am not. I feel weak and helpless and I feel all alone. I have pushed so many people away and I just don't know how to reach back out again.

– Anonymous user[29]

TAKEAWAY: Stigma around SUDs is a significant and sometimes deadly barrier to effective treatment and recovery.

Criminal justice and barriers to treatment

The fact that many individuals with SUDs are using illegal substances also complicates diagnosis and treatment. There are lots of questions that could and should be asked about how the justice system treats users of illegal substances. For example, many question the logic or fairness behind the fact that 5 grams of crack cocaine (generally used within poor communities) carries the same legal penalty as approximately 90 grams of powdered cocaine (generally used by wealthier individuals).[31, 32] While a broader discussion of the justice system is beyond the scope of this report, what is relevant is this: once an individual with an SUD enters the justice system, there are a host of barriers that make it extremely difficult for that person to access effective treatment. And without treatment, that person is more likely to end up back in jail at an enormous cost to us all.

TAKEAWAY: The fact that SUDs can be a criminal issue as well as a health issue is a complicating factor, and those with SUDS who end up in jail face additional barriers to treatment. SUDs, in turn, contribute to recidivism and the high cost of incarceration.

Right now: A dynamic landscape creating opportunities for change

The good news is that the context for the discussion, prevention, and treatment of SUDs is changing. In part, this change is prompted by recent trends. For example, increases in heroin use across a broader range of socioeconomic groups are challenging the stereotypes many people hold about drug users, and several states have legalized marijuana, changing the context of a criminal drug offense.[33, 34] Relatedly, the high and growing cost of prisons when many inmates are non-violent drug offenders has prompted reconsideration of criminal justice policies.[35]

Health care is also shifting the debate. Recent passage of the federal Affordable Care Act (ACA) and the Mental Health Parity and Addiction Equity Act (MHPAEA) has opened access to treatment for SUDs and may create market incentives for providers to use more effective treatment methods. Several national non-profits working on different aspects of SUD prevention and treatment have also been moving toward closer collaboration.

Finally, this is an area that in many ways is ripe with low-hanging fruit. While there's certainly additional need for research and innovation, there's also enormous opportunity in simply connecting SUD patients with what we already know works and in adjusting policies to align with the knowledge we already have. Philanthropists can make a meaningful difference with the tools and knowledge we have right now.

TAKEAWAY: Shifts in conversations around drug policies, changes in health care, new alignments of organizations with experience and capacity in addressing SUDs issues, and the development of new and more effective forms of treatment are changing the SUDs landscape. It is a promising and dynamic time for funders to get involved.

It is not only your body that screams for the substance. Your brain wants it, too. Without heroin, emotional pain feels unbearable.

– Katie, 17 years clean[36]