



# Systemic CARE

## A Public Health Approach to Ending Overdose in America

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The overdose crisis is one of the most significant public health emergencies in the US.<sup>1</sup> The pandemic has exacerbated this crisis, with **overdose rates** increasing as many in-person treatment and support options were shut down. Additionally, the pandemic imposed social isolation is not only a common trigger for drug use but makes it more dangerous because of the risk of overdosing while alone.<sup>2</sup> Over 93,000 people died of overdoses in 2020, a grim new one-year record and a nearly 30% increase over 2019.<sup>3</sup> As the US moves closer to a post-COVID world, we must return some of our focus to tackling the overdose crisis, which has been tearing apart communities in this country for decades and will surely worsen if we don't take swift action.

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Since the late 1990s, the overdose crisis has grown rapidly, devastating communities across the US. Opioids have been fueling this crisis. Millions of people suffer from opioid addiction, and tens of thousands die from opioid overdoses each year.<sup>4</sup> Drug overdoses are now the leading cause of injury-related death in the US,<sup>5</sup> and nearly 70 percent of overdose deaths involve opioids.<sup>6</sup> In fact, a person in the US is more likely to die from an opioid-related overdose than a car crash.<sup>7</sup>

### **The number of people who died of opioid-related overdoses also set a new record in 2020.**<sup>8</sup>

Over the last forty years, the primary US response to drug addiction has been the “war on drugs,” which has defined the drug use of Black people, Indigenous people, people of color, and people with low incomes as criminal and deserving of punishment by incarceration rather than treatment. Meanwhile, white middle and upper class communities have not experienced this criminalization and mass incarceration, and their drug use has often been effectively decriminalized.<sup>9</sup> The war on drugs has devastated Black, Indigenous, and people of color (BIPOC) communities and low-income communities and fueled the massive expansion of the US prison and jail system.<sup>10</sup>

Criminalization and incarceration for addiction not only tear families and communities apart but also are more likely to worsen addiction, and the war on drugs has done nothing to reduce addiction rates in the US.<sup>11</sup> To truly end the overdose crisis, the US must take a public health approach to addiction, most critically ending the criminalization of drug use and mass incarceration of Black people, Indigenous people, people of color, and people with low-incomes.

BIPOC communities have also been on the frontlines of the COVID-19 pandemic: as frontline workers and getting infected and dying at wildly disproportionate rates.<sup>12</sup> The pandemic exposes the fault lines in our broken healthcare system and lays bare the deep racial disparities that have always existed for BIPOC communities in the US,<sup>13</sup> the same deep racial disparities that keep Black people, Indigenous people, and people of color from receiving treatment and support for their opioid addiction.

In 2017, the US federal government declared that the opioid crisis is a national public health emergency.<sup>14</sup> However, the federal response to the crisis has been inadequate and must do more to save lives and support people’s recovery. **We need strategic, targeted public health solutions that are responsive to and grounded in the cultural, economic, and health needs of diverse affected communities—especially BIPOC communities.**

Any response must include robust mechanisms for the participation of a diverse group of local individuals and communities most affected by the crisis in determining solutions and how federal funds are used.

This report will detail the crisis we face and outline what an ideal, comprehensive approach to combating overdose in the US should look like, one that meets public health problems with public health solutions and ends the use of the criminal legal system in addressing addiction. While addressing this issue will require a multi-pronged approach, **the Comprehensive Addiction Resources Emergency Act (CARE) is currently the best legislative means for ending the overdose epidemic.** Modeled on the 1990 Ryan White CARE (Comprehensive AIDS Resources Emergency) Act, a groundbreaking federal response to address the comprehensive needs of people living with HIV, the CARE Act will significantly scale up the federal response to the overdose crisis and, crucially, ground funding in the needs and participation of local communities.





Photo: Carlos Andres Varela

## Spotlight on the Opioid Crisis

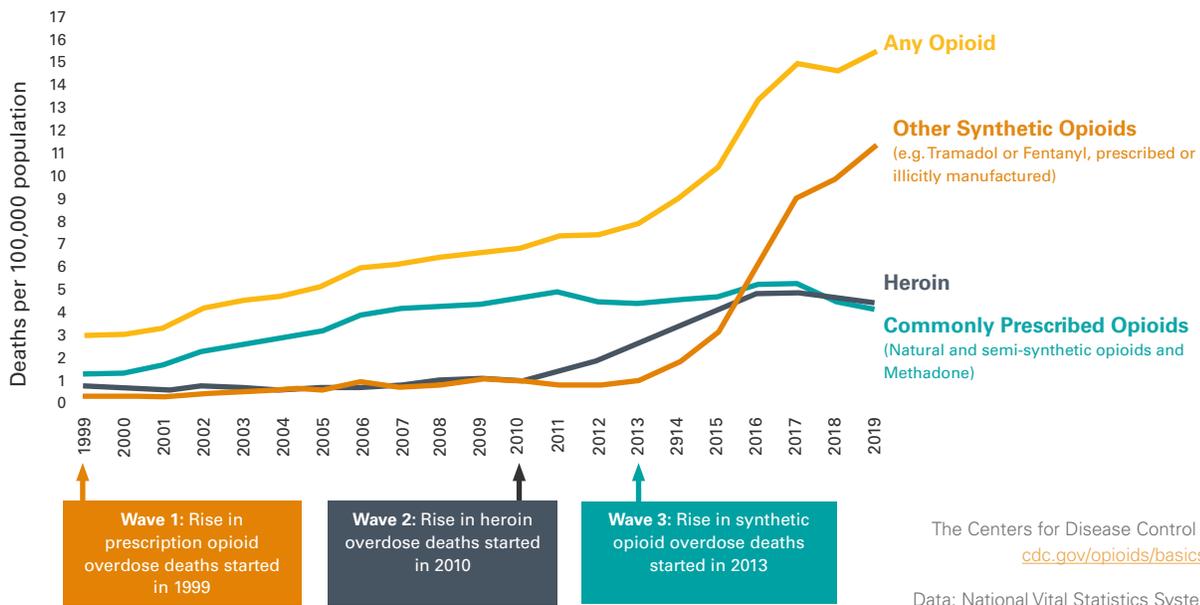
The opioid crisis took root in the late 1990's, when pharmaceutical companies declared that prescription opioid pain relievers would not lead to addiction and healthcare providers began to prescribe them more frequently. Opioids proved to be highly addictive, and by 2017 an estimated 1.7 million people in the US suffered from addiction to prescription opioid pain relievers.<sup>15</sup> **In 2019, 70,630 people died of a drug overdose in the US, with opioids involved in over 70 percent of deaths.**<sup>16</sup>

**This means that in 2019, 194 people died each day in the US from an opioid overdose. Between 1999 and 2019, nearly 500,000 people died from an overdose involving an opioid.**<sup>17</sup>

Opioid addiction not only creates sickness and suffering for individuals but has economic impacts as well. The Center for Disease Control and Prevention (CDC) estimates that the cost of opioid addiction to health care, addiction treatment, "lost productivity," and involvement in the criminal legal system is \$78.5 billion each year.<sup>18</sup>

The opioid crisis first gained notoriety as opioid addiction and overdose deaths skyrocketed in white middle class suburban and rural communities. Prescription opioids (such as oxycodone, morphine, hydrocodone or Vicodin, and Methadone) were largely to blame for this. The other two types of opioids are heroin and other synthetic opioids (most notably Fentanyl, which is a pain reliever much more powerful than other opioids and can be prescribed or distributed and/or made illegally). Since 2013, there has been a dramatic rise in overdose deaths involving synthetic opioids, especially illegally manufactured fentanyl,<sup>19</sup> which has hit Black and Indigenous communities the hardest, as rates of overdose deaths involving synthetic opioids are increasing most rapidly in those communities.<sup>20</sup>

### Three Waves of the Rise in Opioid Overdose Deaths



## Race, the War on Drugs, and the Opioid Crisis

While the opioid crisis impacts all communities, most media, health, political, and policy-making attention has been focused on white rural and suburban communities. This focus on white people's struggles with addiction has helped create a policy response that largely centers an understanding of opioid addiction as a public health problem (i.e. people suffering from addiction need treatment).<sup>21</sup> This stands in stark contrast to decades of the "war on drugs," which has treated drug use and addiction as criminal and deserving of punishment and incarceration and is fueled by racist, anti-Black rhetoric.<sup>22</sup> The war on drugs has devastated many communities of color, especially low-income Black communities. Despite using drugs at about the same rates, Black people are significantly more likely to be incarcerated for drugs and serve longer sentences than white people.<sup>23</sup>

Decades of the war on drugs has also shown us that policing and incarceration do not reduce addiction. **In the over forty years of the "war on drugs," rates of drug use in the US have remained largely constant and drug-related health harms—including spreading Hepatitis C, HIV/AIDS, and other diseases—and overdose deaths have significantly worsened.** In fact, the American Public Health Association calls the war on drugs "a major driver of the HIV/AIDS pandemic."<sup>24</sup>

Incarceration is traumatizing, and it is very difficult to access treatment for addiction while incarcerated. Studies have shown that incarceration increases a person's risk of overdosing once they are released, and currently and formerly incarcerated people have significantly worse health outcomes in general than the general population.<sup>25</sup> **Policing and incarceration are public health crises, and ones that significantly overlap with the overdose crisis.**

While white people have the highest rate of opioid-related overdose deaths of any racial group, in recent years, the rate of opioid-related overdose deaths has increased much more quickly among Black people, Indigenous people, and people of color—and there are indications that rates of addiction in these communities are undercounts.<sup>26</sup> BIPOC communities also have significantly less access to opioid addiction treatment and health care more generally.<sup>27</sup> Black communities in particular have long endured discriminatory and harmful treatment by medical providers. For centuries, healthcare providers in the US have believed that Black people have a higher pain tolerance than other racial groups. This belief continues to be prevalent and to affect Black people's experience with medical providers.<sup>28</sup> These experiences lead Black people to both be less likely to be prescribed appropriate treatment for their pain—including opioid medications—and less likely to be able to access treatment for addiction.<sup>29</sup> BIPOC communities also continue to experience criminalization and incarceration for their drug use.<sup>30</sup>

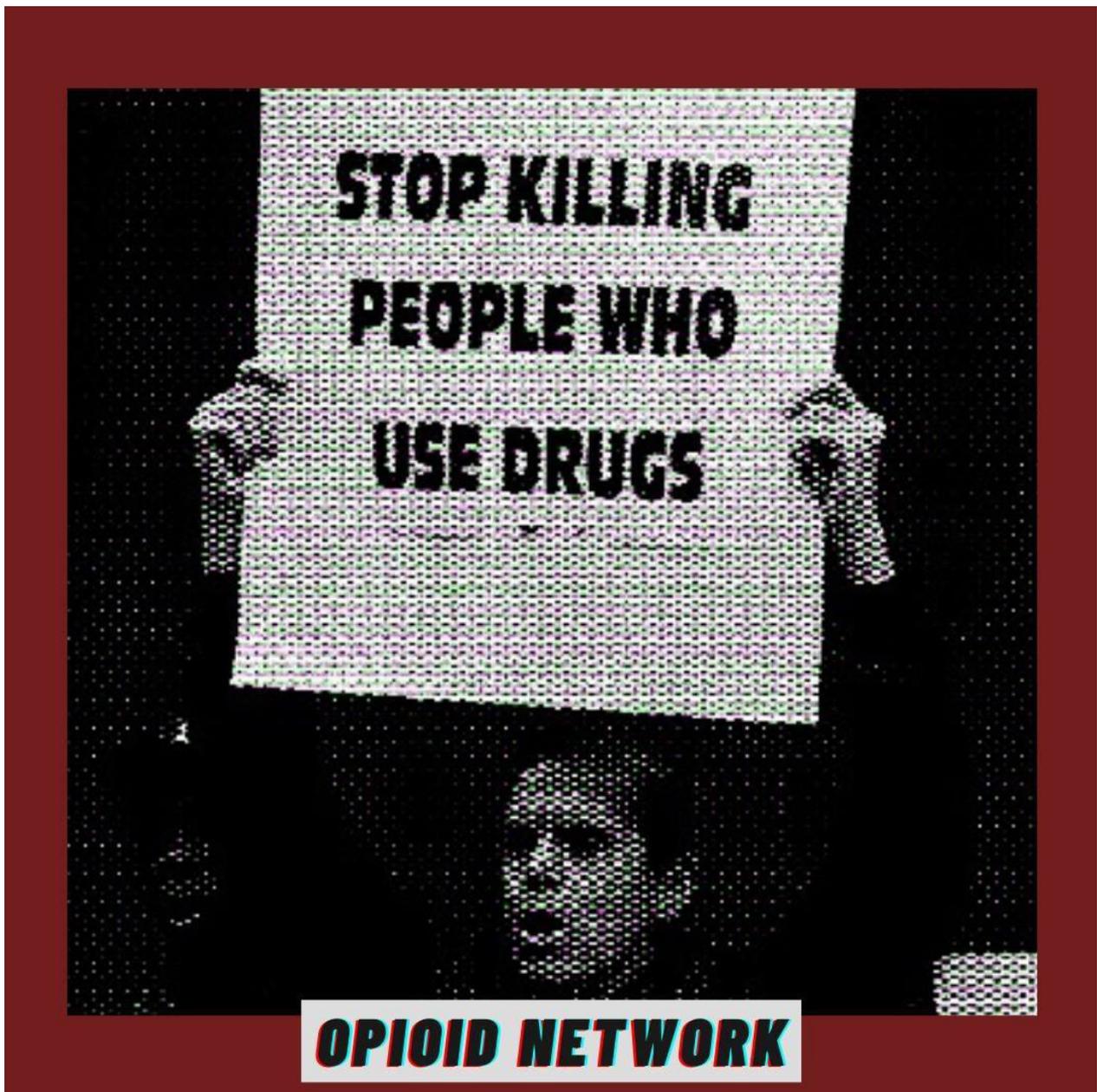


Image: Opioid Network

Moreover, the attention to how white people experience opioid addiction has shaped policy responses, which can be to the detriment of BIPOC communities. Studies have shown that cultural identity impacts people's understanding of health, pain, and illness. Thus, the standard medical approach to pain assessment (which has been defined by middle- and upper-class white cultural norms) can disadvantage BIPOC communities from receiving appropriate treatment.<sup>31</sup>

The experiences of BIPOC communities with opioid addiction and treatment, coupled with the reality of federal and state responses to the crisis that have largely prioritized funding for white communities,<sup>32</sup> reveals the importance of culturally competent, equitable solutions and funding grounded in participatory decision-making processes that center diverse groups of people who are most affected by the crisis.

# A Public Health Approach to Overdose

Over and over again, the US's insistence on approaching public health crises through criminalization and incarceration of poor and BIPOC communities has torn apart lives and communities and worsened those crises. For most of its history, the US has viewed drug addiction in poor and BIPOC communities as moral failing and/or criminal and addressed it through policing and incarceration. This approach is both failed and harmful, and incarceration can lead to a higher chance of overdosing. Treatment for addiction, on the other hand, significantly reduces drug use, related health harms, and the risk of overdose death. Treatment also costs less than incarceration.<sup>33</sup>

To truly end overdose in the US, we must divest from policing and incarceration and invest in the public health measures needed to save lives. That starts with harm reduction, an effort to meet people who use drugs where they are at and keep them safe while they use drugs. Most people who use drugs do not seek to stop. Abstinence programs and incarceration will not protect these people. In fact, the lack of needle-exchange programs nationally is estimated to have cost thousands of lives. Harm reduction, such as needle-exchange programs, can protect the lives and health of people who use drugs, including helping reduce overdose deaths.<sup>34</sup>

In the American Rescue Plan, Congress created the first federal fund exclusively devoted to harm reduction, a monumental first step in approaching overdose as a public health issue while honoring the dignity of people who use drugs.<sup>35</sup> The Department of Health and Human Services also

recently removed burdensome barriers to care for substance use treatment, known as the X-waiver.<sup>36</sup> We must build on this momentum to enact bold legislation that will end the overdose crisis.

A truly comprehensive approach to ending the overdose crisis in the US must include the following:

- An investment in harm reduction commensurate with the crisis we face.
- A funding model that ensures that those directly impacted decide where the money goes and that harm reduction workers have a seat at the table.
- The legalization of and funding for safe consumption sites.<sup>37</sup>
- The full elimination of all waiver and training requirements for healthcare professionals treating substance use disorder.
- Free, widely accessible naran and other overdose reversal medications and unfettered access to clean syringes.
- Action to reduce the high cost of Medication-Assisted Treatment, such as Suboxone.
- Absolutely no funds going to policing or incarceration.
- A mandate that funds allocated for harm reduction do not go to abstinence-only programs or mandatory treatment programs.

There is currently no single bill enacting all of these measures. However, the legislation that offers the most comprehensive, sound approach to addressing the overdose crisis is the CARE Act.

# The Comprehensive Addiction Resources Emergency Act (CARE) Act

The Comprehensive Addiction Resources Emergency Act (CARE) Act is a key piece of legislation that would significantly ramp up the federal response to the overdose crisis. Modeled after the Ryan White CARE Act, this new CARE Act would similarly support prevention services, core medical services, recovery and support services (which can include anything from mental health services and long term recovery services to job training, housing, and legal services), early intervention services, and harm reduction services for people experiencing addiction and their families.<sup>38</sup>

Notably, the new version of the CARE Act includes an explicit prohibition on funding going to policing and incarceration, a bold statement against the US's carceral approach to overdose that signals the shift to public health investments that we need. Additionally, funding will be provided for local programs sending public health professionals rather than police to respond to overdose and mental health crises, and cities will be required to pass Good Samaritan Laws protecting people from arrest for reporting overdoses.

The legislation also prioritizes meaningful decision-making involvement by affected individuals and communities by establishing planning councils modeled on the Ryan White HIV/AIDS program planning councils (see the next section for more details). These planning councils are designed to bring together diverse stakeholders—including people with histories of substance abuse and impacted and historically underserved communities (including tribes and Native

communities, LGBTQ+ communities, communities of color, and rural communities)—to establish priorities for grant funds, help develop and implement plans for the organization and delivery of prevention efforts and treatment, make needs assessments and determine disparities in services, and create processes to get input from community members.

Finally, the bill will keep in place important telehealth and remote care infrastructure that was created in the COVID era. It is crucial to create as many on-ramps to harm reduction as possible, particularly for people facing transportation, accessibility, and economic challenges that prevent them from accessing care in person.



Photo: Vinay Krishnan

# Lessons from the Ryan White CARE Act

In this moment, as we contend with the overlap of the ongoing overdose crisis with the current COVID-19 pandemic, Congress can look to the Ryan White CARE Act as a template for meaningful participation in policymaking by impacted communities, which is vitally important to creating the most effective response to the overdose crisis.

First passed in 1990, the Ryan White CARE Act established the Ryan White HIV/AIDS Program, the first and most comprehensive program to provide care and treatment for people with HIV/AIDS.<sup>39</sup> The Ryan White HIV/AIDS Program is the largest federal program designed specifically for people with HIV, with more than half of people in the US living with HIV—or more than half a million people—receiving services through the program. Most Ryan White clients are low-income, male, people of color, and LGBTQ+.<sup>40</sup>

From its very inception, the Ryan White Care Act leveraged the expertise and knowledge of people living and working in impacted communities. Written by frontline leaders at AIDS Action, the involvement of frontline leaders was crucial to ensuring that policy solutions were reflective of the on-the-ground realities of accessing HIV/AIDS services and care.<sup>41</sup>

The Ryan White HIV/AIDS Program fills gaps in the existing HIV care system,<sup>42</sup> functioning as the “payer of last resort” by providing care for individuals who are uninsured or underinsured.<sup>43</sup> Importantly, it provides holistic care—not just primary medical care but also support services, such as case management, housing, child care services, legal services, food and nutrition services, dental services, and some mental health services, among many other supports.<sup>44</sup> These critical supports are typically not covered by health

insurance but are essential to helping people survive and stay in care.<sup>45</sup>

Today, the Ryan White HIV/AIDS Program is widely recognized for its success in improving outcomes for people living with HIV/AIDS.<sup>46</sup> For example, in 2017, 85.9 percent of program clients were virally suppressed, compared to the national average of 59.8 percent.<sup>47</sup> According to HIV care providers, the program not only provides excellent care to people living with HIV/AIDS, but is important to public health generally as it serves as “a successful template beyond HIV/AIDS care.”<sup>48</sup>

## The Planning Council Model: Key Lessons

A portion of the Ryan White HIV/AIDS Program funding can be used to support a planning council or similar body that will lead a community planning process.<sup>49</sup> In 2017, there were 52 planning councils or planning bodies in areas hit hardest by the HIV/AIDS epidemic.<sup>50</sup>

The primary role of a planning council or body is to assess the service needs of people living with HIV in the area and determine the type of services and amount of funding required to meet those needs. Planning councils conduct needs assessments, provide guidance about service models, identify target populations for care, and strategize about the most effective ways to meet priorities.<sup>51</sup>

Although each planning council is different, “consumers,” or people living with HIV/AIDS who receive Ryan White-funded care, must comprise at least 33 percent of the council. Additionally, consumer membership and overall council membership must reflect the characteristics of the local epidemic along lines of race, ethnicity, gender, and age.<sup>52</sup>

The decision-making role of directly impacted individuals is the bedrock of the planning council model's effectiveness. "Consumers" draw from their personal experience with navigating the HIV/AIDS care system to make concrete recommendations about how best to serve people. The insights they bring, based on the barriers they confront and gaps in service that they encounter, are crucial to designing programs that reflect on-the-ground realities. These are critical perspectives that health care providers are unable to provide. For example, one study of a joint planning council and consortium in Jacksonville, Florida, found that people living with HIV/AIDS prioritized "services that were difficult to obtain (transportation), or those that made them feel better (alternative therapy) while the providers were more concerned with medical treatment."<sup>53</sup> "Consumers" rated health education and risk reduction much higher than providers did, "most likely because this category provides them with information regarding how to access services, which they feel is lacking in the current system."<sup>54</sup>

Participation from "consumers"—when included as full partners in decision-making and not just as a source of input<sup>55</sup>—has been critical to ensuring that funding prioritizes the most important services for impacted communities.

The planning council structure is also a successful model for collective decision-making and problem solving. Research on planning councils in Broward County and Palm Beach County, Florida, found that they were consensus-oriented and succeeded in reaching consensus regularly despite challenging dynamics of deliberation, communication, and resource allocation. The study concluded that representation and participation of people living with HIV, service providers, non-elected community leaders, and other stakeholders in decision-making resulted in "collective problem solving."<sup>56</sup>

## Elements Needed for Success

In designing participatory mechanisms for addressing today's public health crises, Congress can also take lessons from the challenges and growth areas of the planning council model. The above described 2017 assessment of planning councils/bodies identified the following components necessary for planning council success:<sup>57</sup>

- **Adequate resources:** Councils each have the same responsibilities but widely differing resources, which translates to widely varied capacities and results. For example, some groups are able to design and administer a sophisticated needs assessment to evaluate the priority areas and target populations for care, while others administer a very basic survey. Planning councils need adequate resources to be able to carry out their jobs successfully.
- **Training and technical assistance:** Planning councils need increased support in the form of targeted technical assistance and training, the development and sharing of materials, and ongoing support.
- **Recruitment:** Recruiting and maintaining representative membership can be a challenge for councils. In particular, the overrepresentation of providers can result in potential conflicts of interest. Councils need additional guidance, flexibility, and training/technical assistance to maintain representative membership.
- **Independence:** Planning councils must be independent bodies that work in partnership and receive support with the grant recipients, but not under their direction.

# Conclusion

The federal government must take action to address the ongoing overdose crisis that has devastated families and communities for decades. That action must be rooted in a public health approach that centers the voices and needs of those most impacted by the crisis—including people who use drugs and people engaging in harm reduction work—and includes an end to mass incarceration and the criminalization of drug use and addiction, which has devastated BIPOC communities and low-income communities and worsened public health outcomes for people who use drugs.

**The Comprehensive Addiction Resources Emergency Act (CARE) Act is the best current response to the overdose crisis. Congress must act to pass this much needed legislation then build on it to create a comprehensive, holistic approach to ending overdose,** which must include:

- An investment in harm reduction commensurate with the crisis we face.
- A funding model that ensures that those directly impacted decide where the money goes and that harm reduction workers have a seat at the table.
- The legalization of and funding for safe consumption sites.
- The full elimination of all waiver and training requirements for healthcare professionals treating substance use disorder.
- Free, widely accessible naran and other overdose reversal medications and unfettered access to clean syringes.
- Action to reduce the high cost of Medication-Assisted Treatment, such as Suboxone.
- Absolutely no funds going to policing or incarceration.
- A mandate that funds allocated for harm reduction do not go to abstinence-only programs or mandatory treatment programs.

**Only a true shift in national policy to a public health approach to public health problems will save lives, keep communities whole, and honor the dignity of people who use drugs.**

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