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# *The Ripple Effect: The Impact of the Opioid Epidemic on Children and Families*

*Recommendations for an Action Agenda Based on a  
Multidisciplinary Meeting*

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**“My mom is on the floor... No, she’s not awake.  
She’s changing color.”  
“Keep talking to her.”  
“Mom, wake up! Mom, wake up! Mom, wake up!”**

— Conversation between 911 operator and nine-year-old child from “Heroin’s Children,” Top Documentary Films, 2017  
<https://topdocumentaryfilms.com/heroin-children/>

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**“My dad died of a combination of opiates and prescription drugs... The only thing I remember is my brother telling me it’s not going to be okay, it’s never going to be okay, but we’re going to pretend it’s going to be okay.”**

— Alexis Lightle, 17 years old, from “Heroin’s children: My life inside the US opioid crisis,” *Al Jazeera*, December 26, 2017  
<https://www.aljazeera.com/indepth/features/heroin-children-life-opioid-crisis-171030083501156.html>

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**“You get this call...  
‘Come pick up your grandkids.  
If you don’t they will go into foster care.’ And then everything in your life changes.”**

— Participant in kinship caregiver program from “The opioid crisis is making grandparents parents again,” *Vox*, October 30, 2017  
<https://www.vox.com/videos/2017/10/30/16562000/opioid-crisis-grandparents-raising-children>

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**“I see it, and I’m like, I was a piece of freaking [expletive],” she said. “That was me in active use. It’s not who I am today.” But she also wondered: Why didn’t anyone help her daughter? She was furious that bystanders seemed to feel they had license to gawk and record instead of comforting her screaming child.**

— Mandy McGowan, 38 years old, reaction to her overdose being videotaped by bystanders  
“Addicts Pick Up the Pieces,” *New York Times*, December 12, 2018, p. A22.

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Prior to working at United Hospital Fund, Suzanne was the assistant director of the Global Health Policy Center at the Center for Strategic and International Studies in Washington, DC. She has also worked with Catholic AIDS Action in Namibia, Nationwide Children's Hospital, and Boston Medical Center. Suzanne is a member of the Bennington College Board of Trustees and the national Children's Health Leadership Network. In 2018, she was named to City & State New York's "40 Under 40" list and *Crain's New York's* list of 100 notable women in health care.

She holds a BA from Bennington College and an MS degree from the Harvard T.H. Chan School of Public Health.

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Ms. Levine is the editor of *Always on Call: When Illness Turns Families into Caregivers* (2nd ed., Vanderbilt University Press, 2004) and editor of *Living in the Land of Limbo: Fiction and Poetry about Family Caregiving* (Vanderbilt University Press, 2014). Her most recent book is *Navigating Your Later Years For Dummies* (Wiley and AARP, 2018).

In 1993, Ms. Levine was awarded a MacArthur Foundation Fellowship for her work in AIDS policy and ethics. In 2016, she was named one of the Top 50 "2016 Influencers in Aging" by the digital publication *Next Avenue*. In 2018, she received the Friends of the National Library of Medicine Donald A. B. Lindberg Distinguished Health Communications Award.

She holds a BA from Cornell University and an MA in public law and government from Columbia University, where she also studied at the Russian Institute.

## Foreword

The devastation of the opioid epidemic is pervasive: lives lost, futures derailed, and communities shattered. While hitting the economically and socially disadvantaged particularly hard, America's deadliest drug crisis has left no demographic group untouched.

Despite a significant volume of news and research on the tragic toll of opioids, one aspect has gone relatively unnoticed: the impact on children and families.

A United Hospital Fund project is working to change that by shining a light on the epidemic's long-lasting and destructive "ripple effects" on children and adolescents whose parents are addicted and on kinship caregivers who often end up caring for these young people.

The report contains takeaways and lessons from a two-day meeting hosted by United Hospital Fund in October of 2018 during which a group of researchers, clinicians, and policymakers from across the country deliberated on how best to address this vital issue.

I believe that their observations and recommendations, outlined in the following pages, create a blueprint for meaningful action. They also demonstrate that when it comes to assisting children and families affected by opioid addiction, we already know of many policies and interventions that work—we need to take the next step of putting what we know into practice in a sustainable way.

To do this effectively, we will need broad and sustained partnerships. As this report notes, silos in government and service organizations hamper effective coordination and communication. Overcoming these silos—some of which exist within the health care system itself—is critical to making progress now and in the future.

At UHF, we take a long-term perspective in tackling persistent problems. In the case of opioids, our staff and partners recognize that the consequences of addiction will continue for years and that an effective response must include systemic solutions.

I hope you find this report useful and enlightening. More importantly, I hope it might instill a sense of urgency and even hope—working together, there is a lot we can do to help children and families in the path of opioid addiction.

Anthony Shih, MD  
President  
United Hospital Fund

## Executive Summary

While opioid addiction is widely recognized as a national epidemic, one aspect of the crisis has received little attention: the short- and long-term effects on children and adolescents whose parents are addicted. An individual's substance use disorder (SUD) sends ripples through families and communities and ignoring these ripples can cause long-lasting consequences. Children affected by familial SUD are at increased risk of similar problems themselves, and kinship caregivers who often step in to care for these children are also likely to have increased physical and mental health needs.

The opioid epidemic affects families in many ways. To begin to illuminate the magnitude of the “ripple effect,” and the challenges facing family members, United Hospital Fund hosted a two-day meeting of multidisciplinary researchers, clinicians, and policymakers in October 2018. The agenda was focused on five main populations: women of childbearing age; young children and their mothers; children exposed to trauma; youth caregivers; and kinship caregivers.

Though the multidisciplinary group did not attempt to reach consensus, participants generally agreed on these four broad areas for action:

- Pervasive stigma, misunderstanding, and fear about SUD and treatment;
- Failure to make the ripple effect a public and political priority, which exacerbates a shortage of family-centered treatment options and inadequate funding for programs that work;
- Silos in government and service organizations that lead to lack of communication, coordination, and collaboration, particularly about risk assessment of children and reporting requirements;
- Missed opportunities to identify children at risk and provide them and their families with essential support.

The need to address these problems is urgent. Some evidence-based programs in place today are meeting the unique needs of these groups, and innovative approaches are emerging, but the response to date has been inadequate. We need to simultaneously generate more knowledge about what works for families, while implementing best practices. The good news is that existing capabilities in agencies and programs supporting children and families can be leveraged along with lessons from prior public health crises—the HIV/AIDS and crack cocaine epidemics, in particular—to formulate a response that helps children thrive and that preserves families. Following is a quick summary of the action agenda categories, which are detailed on pages 19 – 26 of this report:

### **Reduce stigma and misunderstanding of opioid use and treatment**

- Promote the use of nonjudgmental, nonpunitive language.
- Develop educational programs on the nature of SUD and its treatment.
- Learn how stigma was reduced for other diseases, such as cancer and HIV/AIDS.
- Create opportunities for people affected by the opioid epidemic to tell their stories.

### **Make investing in a response to the ripple effect a priority**

- Encourage integrated services for parents and children.
- Increase the availability of family-based mental health services.
- Invest in evidence-based and promising prevention and intervention programs that promote youth development.
- Provide technical assistance for implementation and evaluation.
- Quantify the magnitude of the ripple effect.
- Reduce geographic and racial/ethnic disparities in access to services.

### **Ensure that government and private agencies work as a team**

- Establish a coordinated prenatal and postnatal care plan for women with SUD.
- Emulate and expand community-based, collaborative forums to address gaps in helping families.
- Develop comprehensive state, city, or regional plans.

### **Identify children at risk as early as possible**

- Create protocols that help first responders identify children present at potentially traumatic events and connect the child to trauma-informed care.
- Encourage schools to be trauma-informed.
- Support kinship caregivers in identifying and responding to signs of trauma in children.
- Develop quantitative and qualitative research about youth caregivers.



Above all, meeting participants stressed that there is reason for hope. In many domains, we know what needs to be done—we just need to commit the resources and mobilize public support to do it. This requires a concerted effort involving many stakeholders, a willingness to confront tough problems, and an “all hands on deck” approach at every level of society. Taking these actions will lead to meaningful improvements not just for children affected by the opioid epidemic, but for those facing all kinds of adversity.

## Introduction

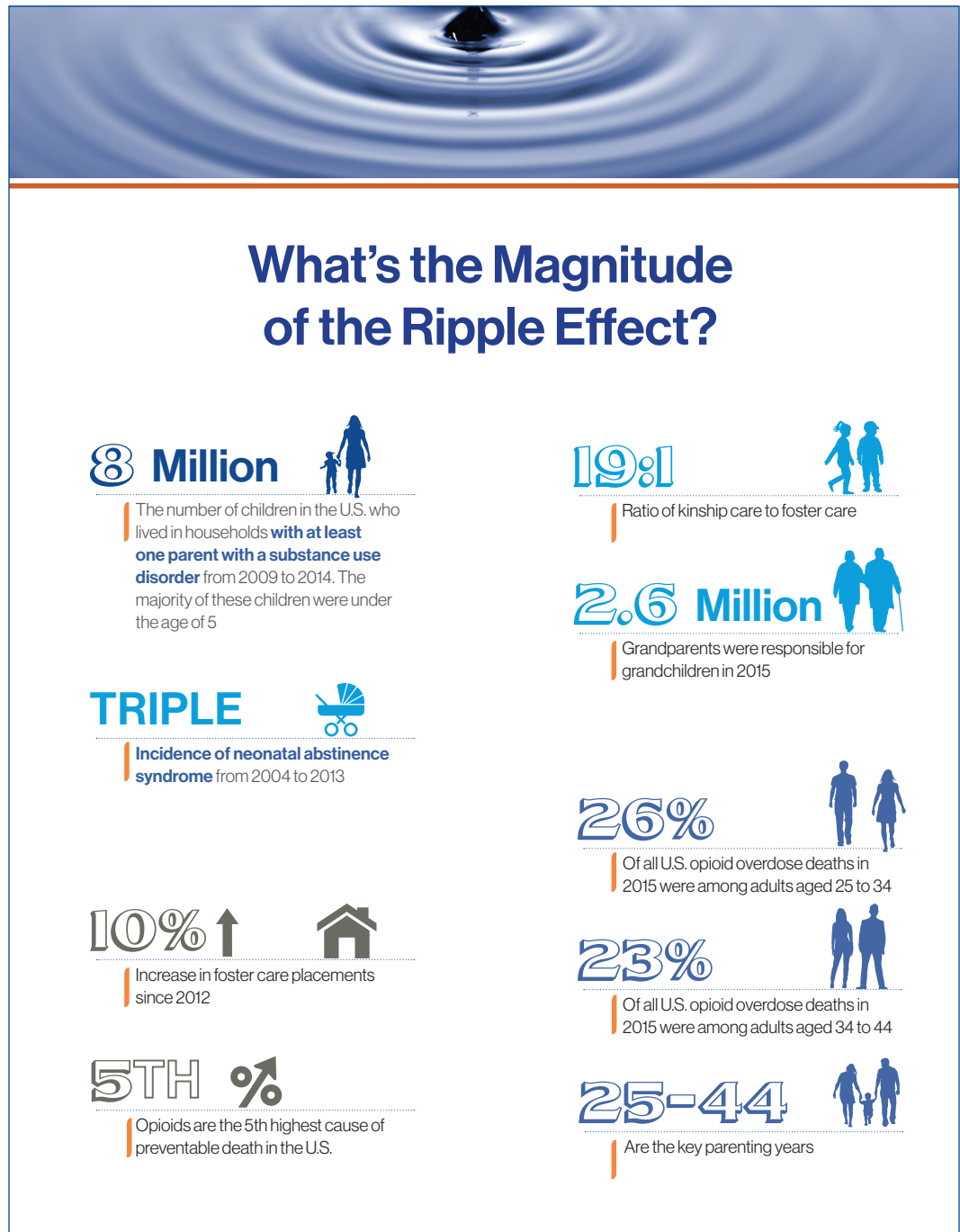
The United States is in the grip of an opioid crisis. Government policymakers, health care providers, and community agencies are working to identify individuals misusing opioids and enroll them in appropriate treatment programs. Concurrently, law enforcement agencies are focused on controlling the supply of drugs fueling the epidemic—not just prescription opioids but, increasingly, street drugs like heroin and fentanyl.<sup>1</sup> While these are important aims, they fail to address a serious and long-lasting problem: the impact of the epidemic on the children and families of people with a substance use disorder (SUD).<sup>2</sup>

The statistics on overdoses, deaths, and economic costs are stunning, but they do not fully convey the human toll of the epidemic. (See Figure 1.)

Children and youth affected by familial SUD are at risk themselves for disrupted lives, school problems, trauma-related anxiety, and potential use of the drugs that caused the problems in the first place. Children are often hidden from view until a crisis in the family (overdose, death, arrest, incarceration) occurs; even then, they are seldom identified as needing help. The opioid epidemic is a multifactorial and multigenerational problem, and the solutions must recognize all these complexities.

To provide a broad view of the widespread and costly impact of the opioid epidemic, United Hospital Fund (UHF) convened a meeting on October 3-4, 2018, supported by the Alfred P. Sloan Foundation, with the collaboration of the Milbank Memorial Fund. The title of the meeting, “The Ripple Effect: Children and Kinship Caregivers Affected by the Opioid Epidemic,” was intended to convey the far-reaching scope of the problem. The goal of the meeting was to produce a high-level policy and programmatic agenda to address the effect of the opioid crisis on women, children, and families. This paper lays out that agenda.

Figure 1. What's the Magnitude of the Ripple Effect?



## Background

Picture a stone dropping into a pool of water. The stone represents a person with SUD. The first set of ripples it creates includes the people who experience the immediate impact: the person's children, partners or spouses, as well as parents and siblings who become kinship caregivers for the children. Further from the center of the pool and more episodically involved are ripples that represent providers of health care and social services, schools, pharmacies, police and law enforcement, employers and coworkers, faith communities, and other aspects of community life. And the ripples do not end when the water reaches shore. Children who experience adversity early in life, including family opioid use, carry those experiences into adolescence and beyond. Even if the opioid epidemic were stopped cold today, there would be ripples far into the future. (See Figure 2.)

Figure 2. The Ripple Effect Expanding from Mother to Children and Beyond

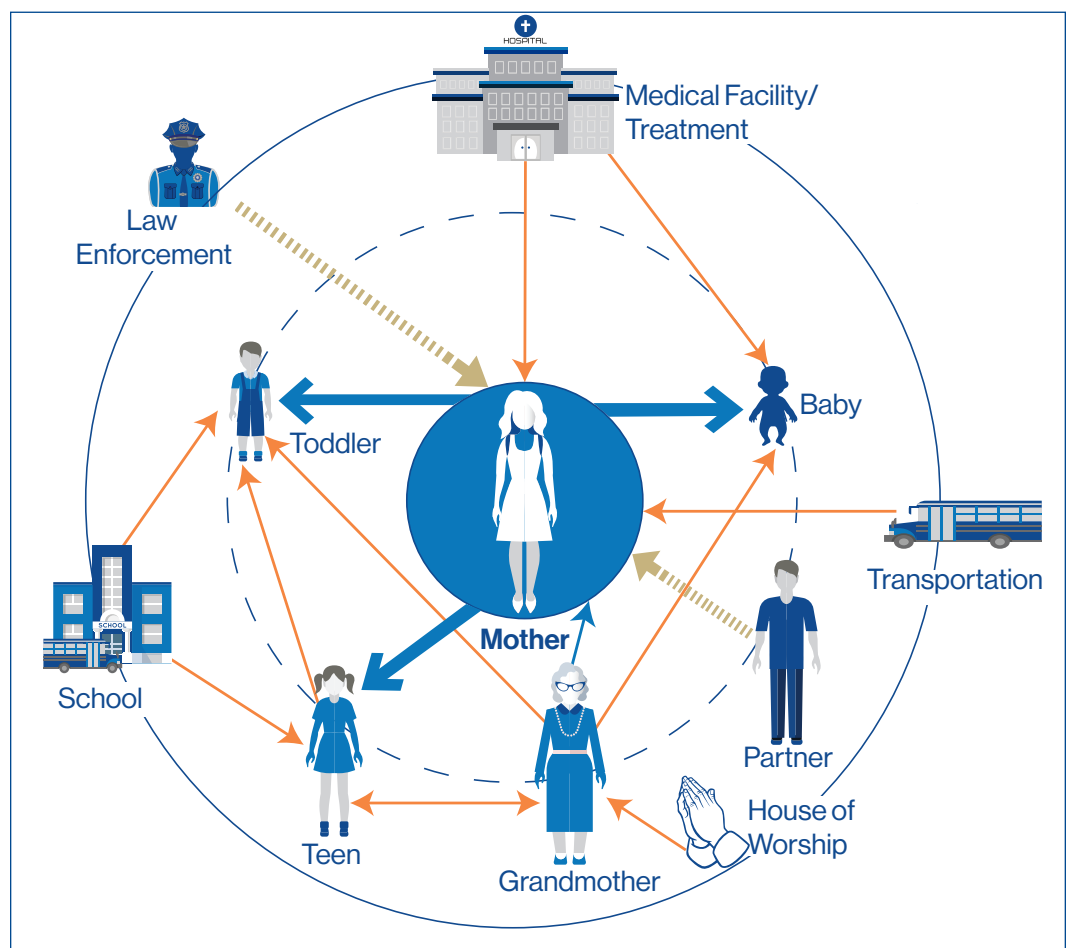


Figure 2 is an example of the ripple effect as it expands from mother to children to other family members and community services. The direction of the arrows indicates who is caring or providing services for whom; bidirectional arrows indicate

*reciprocal relationships. The thicker arrows indicate frequent interactions; medium lines indicate regular interactions; and dashed lines indicate occasional or erratic interactions. The primary circle contains the mother; the next circle includes children and other family members; and the outer circle represents community and other services. This model can be used to show even more people and agencies and further distances. This illustration is based on the concept of the CareMap, created by Rajiv Mehta, developer of the Atlas of Caregiving (<http://www.atlasofcaregiving.com>) and is used by permission.*

The 40 participants in the 2018 meeting included leaders from government agencies, pediatrics, maternal and child health; child welfare agencies, family caregiving organizations; addiction medicine, behavioral health, and law enforcement (see Appendix A). Among them were researchers, program leaders, and policymakers. Participants were primarily from New York, with additional experts from Ohio, West Virginia, Massachusetts, Vermont, Wisconsin, and Connecticut. Four New York State commissioners and two New York City commissioners attended or sent deputy commissioners. The federal government was represented by a speaker from the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Several participants had been involved in responses to the HIV/AIDS and crack cocaine epidemics, which significantly informed the discussion.

As part of their effort to inform UHF's policy and programmatic agenda, participants described programs they have developed, operate, or know about that are designed to serve new moms, children, and kinship caregivers dealing with SUD. While research is still emerging, several programs were selected to be shared during the meeting because they illustrate relatively new collaborative and innovative approaches to caring for children and families in the ripple effect. Some of these programs are highlighted in this report.

A common theme emerged: the need to help children thrive while stabilizing and supporting their families. Attendees were acutely aware that while the current opioid epidemic creates urgency, many of the challenges facing families are not new—nor are they limited to opioid use or other substance use disorders. The issues raised by opioids are a stark reminder of the many children and families who all too regularly face adversity from a wide range of sources, including poverty, violence, discrimination, and other social ills. Our call to action for children and families affected by opioids applies to all children in distress.

## Organization of the Report

This report presents a summary of the October 2018 meeting and reflections on the discussions. The aim of the meeting was not consensus, but rather to call attention to a range of needed responses and barriers to an effective strategy. Participants generally agreed on the key areas for action; however, unless specifically noted, the authors are solely responsible for the views expressed in the report.

This report first describes the main populations affected by the ripple effect: women, particularly those of childbearing age; followed by newborns, infants, and toddlers; children of all ages exposed to traumatic events; youth caregivers; and kinship caregivers, primarily grandparents (see Figure 2). Men are part of this story as fathers, brothers, partners, uncles, grandfathers, and friends; they too need to be part of the solutions.

Some ripples affecting these populations overlap. The infant born to a mother with SUD may have siblings. The family may have more than one person with SUD or a history of alcohol or other substance use. The grandmother who has health problems and few financial resources may now face a level of responsibility for which she is unprepared because of previous traumas and losses. Each family's story is different, but there are common elements.

The report then describes four overarching problem areas that emerged at the meeting and from prior discussions with participants and other experts:

- Pervasive stigma, misunderstanding, and fear about SUD and treatment;
- Failure to make the ripple effect a public and political priority, which exacerbates a shortage of family-centered treatment options and inadequate funding for programs that work;
- Silos in government and service organizations that lead to lack of communication, coordination, and collaboration, particularly regarding risk assessment of children and reporting requirements;
- Missed opportunities to identify children at risk and provide them and their families with essential support.

The report concludes with specific recommendations for each area.

## **A Brief History of the Opioid Epidemic**

*The opioid epidemic is not America's first drug crisis, but it is its deadliest. While opioids overprescribed for pain relief are usually cited as the cause of the epidemic, the problem goes beyond this class of drugs and includes a broad range of substances. Some, such as heroin and morphine, are opiates—that is, derivatives of the sap of the opium poppy. Opium has been used for centuries to treat pain and other conditions as well as for its soporific effects. Some drugs, such as oxycodone, fentanyl, and hydrocodone are synthetic products developed in the late 20th century. Methamphetamines and cocaine and combinations of uncertain origin and formulation add to the mix. The prominence of specific drugs has varied over time, but the current epidemic took root on the soil of prior epidemics. Among the more than 70,237 drug overdose deaths in 2017, the sharpest increase occurred among deaths related to synthetic opioids other than methadone, including fentanyl and fentanyl analogs, and tramadol; deaths from these drugs increased 45 percent from 2016 to 2017.<sup>1</sup> This increase, combined with a higher suicide rate, has lowered life expectancy in the U.S. for the second year in a row.*

*The first opiate epidemic took place over a century ago, when doctors liberally prescribed morphine to their patients, mainly women, for all kinds of ailments.<sup>2</sup> Cocaine, derived from coca leaves, was recommended as a cheap and readily available tonic, even for children. By the 1920s the deleterious consequences of these laissez-faire policies were obvious. The federal government and states enacted laws to ban certain drugs and incarcerate those who used or sold them. According to David Courtright, author of *Dark Passages*, a history of drug use in the United States, substance abuse then began to be associated not with middle-class, white suburban women (as in the first opioid epidemic) but with lower-class, nonwhite men in urban centers.<sup>3</sup> Policies criminalizing drug use and trafficking drove users underground and laid the foundation for the stigma that continues to hamper efforts to treat opioid users today.*

*While some synthetic opioids were available in the late 1980s and early 1990s, the turning point came in 1996, when a new form of oxycodone—OxyContin—was introduced. This drug was formulated to release more slowly and last longer. Its introduction was accompanied by a major marketing campaign that erroneously claimed a low, almost nonexistent potential for addiction and included financial and other inducements to physicians to prescribe the drug and encourage their colleagues to do the same. Eventually, one company admitted to fraudulent marketing, but the penalties were small compared to the profits—and the damage was done.<sup>4</sup>*

*According to the Centers for Disease Control and Prevention, the rise in opioid overdose deaths can be outlined in three distinct waves: “The first wave began with increased prescribing of opioids in the 1990s, with overdose deaths involving*

*prescription opioids (natural and semisynthetic opioids and methadone) increasing since at least 1999. The second wave began in 2010, with rapid increases in overdose deaths involving heroin. The third wave began in 2013, with significant increases in overdose deaths involving synthetic opioids—particularly those involving illicitly-manufactured fentanyl (IMF). The IMF market continues to change, and IMF can be found in combination with heroin, counterfeit pills, and cocaine.”<sup>5</sup>*

*Are we at a crossroads? Recent data suggest a slight downturn or at least a leveling of overdose deaths, which is an important but incomplete measure of substance use disorder. And some communities have brought deaths down by a coordinated and comprehensive prevention and treatment response. But it is too soon to claim victory; and for the children and families already devastated by substance abuse disorder, the effects of the epidemic will be long-lasting.*

1. Holly Hedegaard, Arialdi M. Minimo, and Margaret Warner. “Drug Overdose Deaths in the United States, 1999-2017.” NCHS Data Brief, No. 329. National Center for Health Statistics. Available at: <https://www.cdc.gov/nchs/data/databriefs/db329-h.pdf>.
2. Carol Levine, “New Opioid Epidemic: Another Long Day’s Journey.” Hektoen International. Available at <http://hekint.org/2018/06/15/new-opioid-epidemic-another-long-days-journey/>.
3. David T. Courtright, *Dark Passages: A History of Opiate Addiction in America*. Cambridge, Massachusetts: Harvard University Press, 2001.
4. Barry Meier, *Pain Killer: An Empire of Deceit and the Origin of America’s Opioid Epidemic*, 2nd edition. New York, New York: Random House, 2018.
5. Centers for Disease Control and Prevention. “Understanding the Epidemic.” (December 19, 2018). Available at: <https://www.cdc.gov/drugoverdose/epidemic/index.html>.



## Populations Affected by the Ripple Effect

### Parents, Especially Mothers

Preventing and effectively responding to the ripple effect requires addressing its most frequent origin: parental substance use disorder. While all parental SUD requires attention, the needs of women warrant special emphasis. Pregnant women who use opioids during pregnancy, even as part of treatment, need support to minimize effects on the newborn's health. This does not end with the birth; mothers are most commonly the primary caregivers of children. Yet the unique needs of women, especially women of childbearing age, have often been ignored in the response to the opioid epidemic. Recognizing the critical role of women in family health should not be used as justification for blaming, stigmatizing, or criminalizing women—rather, it should illuminate the need for more resources, research, and supportive efforts.

For women, especially those of childbearing age, the opioid crisis is characterized by gender differences in opioid prescribing, susceptibility to dependence, and access to treatment. While men are more likely than women to die from opioid overdose, deaths among women are increasing more rapidly than among men. The death rate for men rose from 8.2 per 100,000 in 1999 to 29.1 in 2017; for women, it went from 3.9 in 1999 to 14.4 in 2017.<sup>3</sup> Women are at a higher risk of becoming dependent on opioids and of doing so more rapidly. Women are more likely than men to suffer from acute and chronic pain and to be prescribed opioids for these conditions. Women are also more likely than men to have co-occurring anxiety and depression with SUD.<sup>4</sup>

The factors that lead to more rapid dependence—while important in their own right because of how they endanger women's health—become especially problematic for women who are of childbearing age or pregnant. Both SUD treatment facilities and women's health providers are, in general, underequipped to care for pregnant women and mothers with SUD. For most pregnant women, including those who use drugs, the health of the baby is critically important. There are many incentives for women to seek treatment at this vulnerable time, but there are also real and perceived risks.

Like many people with SUD, pregnant women worry they will be judged by health providers and the public if they seek care. An even graver fear is that acknowledging drug use to a health care provider, testing positive for substance use, or giving birth to a child with neonatal abstinence syndrome (NAS) will result in loss of custody of the newborn and possibly other children. Depending on state law or health care provider policy, this may happen even if a woman is undergoing medication-assisted treatment (MAT),<sup>5</sup> which is considered the gold-standard for treating opioid use disorder.

A physician who participated in the meeting notes: “The two most common questions women with opioid use disorder ask during prenatal care are: ‘Will my baby be okay?’ and ‘Will my baby be taken away?’” Providing clear-cut answers is challenging. The response to the question about losing custody can be complicated by a lack of agreement, communication, and coordination between obstetricians, addiction specialists, and child welfare agencies. Most health providers and child welfare agencies have little interaction with one another, often operate under different concepts of what constitutes a reasonable risk to the safety of a child and what is in the best interest of a mother, and lack means for jointly developing a plan of safe care for mother and child.<sup>6</sup>

Underscoring this challenge is a widespread misunderstanding of NAS. While this condition is often described as being “born addicted to drugs,” that label is inaccurate—just as the labels of “crack babies” and “AIDS babies” in earlier epidemics depicted these newborns as “victims” rather than sick infants who needed an array of treatment interventions as well as nurturing and bonding. Babies with NAS are not addicted to opioids; they are experiencing withdrawal from the opioids transmitted in utero by their mothers. Recent innovations in care for babies with NAS can decrease days in treatment, shorten time in the neonatal intensive care unit, cut hospital length of stay, and provide more opportunities to bond with the mother—these are promising practices, although more research is needed to ensure they result in improved outcomes for mother and child.<sup>7</sup>

## **Children and Recovering Mothers Collaborative**

The Children and Recovering Mothers (CHARM) Collaborative in Burlington, Vermont, provides comprehensive care coordination for pregnant women with opioid use disorder and consultation for child welfare, medical, and addiction professionals across Vermont. Established in 2002, the Collaborative comprises 10 organizations, including the state Department for Children and Families, Department of Corrections, and Department of Health, as well as Vermont health care and substance abuse treatment providers. Its goal is to ensure the delivery of a healthy baby and to help mothers and children remain together or be reunified safely. CHARM uses multiple intervention opportunities across service systems and professionals, beginning before pregnancy and continuing throughout a child’s early years. Collaboration across systems includes mutual values and principles of collaboration, screening and assessment, joint accountability and shared outcomes, information and data systems, training and staff development, and working with communities and supporting families. [https://ncsacw.samhsa.gov/files/Collaborative\\_Approach\\_508.pdf](https://ncsacw.samhsa.gov/files/Collaborative_Approach_508.pdf)

Finding a SUD treatment facility can be difficult in all cases but finding one that addresses the special needs of women is even more challenging. Most treatment programs are designed for men; they don't consider women's needs for child care,<sup>8</sup> relationship counseling, and screening for depression and anxiety. Even inpatient programs that do allow children tend to be available only for babies and children under age five. Though some women-only treatment programs exist, they are not widely available.

## **Young Children and their Developmental Needs**

The immediate years following birth are a period of great opportunity and risk. Young children are particularly sensitive to toxic environments, including high levels of stress that can disrupt healthy development. Even so, children can also be remarkably resilient. The key to thriving in the face of adversity is often the presence of at least one stable and committed relationship with a supportive parent, caregiver, or other adult.<sup>9</sup> For this reason, child health and well-being is intrinsically linked to caregiver health and well-being.

Despite this understanding of child development, policymakers have paid far too little attention to supporting mothers with SUD and their newborns. In states that haven't expanded Medicaid, many mothers are likely to lose health coverage 60 days post-discharge, severely limiting their access to health care. Even when they have insurance, mothers and children can rarely access "two-generational" programs that simultaneously serve parent and child; these programs integrate services, provide supports to strengthen families, and help reduce toxic levels of stress for families.

Stressors for these young families are plentiful. Babies affected by NAS may have mild to severe symptoms that can be challenging to manage. These babies are often fussy, have low birthweights, need special formulas, and have diaper rash and skin conditions, as well as other comorbidities. Mothers with SUD may also have depression and anxiety and be overwhelmed with managing the many challenges that come with parenting while trying to maintain recovery. These challenges include logistical problems, such as scheduling doctor's appointments, child welfare agency involvement, and transportation. The presence of other people with SUD in the household, if they are not engaged in treatment, may undermine recovery efforts and pose risks to children, including accidental ingestion of drugs. On top of this, like all new mothers, they are adjusting to hormonal changes and new demands on their time and attention. A woman's likelihood of relapse steadily increases after birth, peaking at around seven-to-12 months postpartum.<sup>10</sup>

Integrated pediatric care and maternal care models that include behavioral health and social supports would better serve these families, as would expansion of home visiting services. To date, however, these types of care models are not widespread.

## Supporting Our Families Through Addiction and Recovery

Supporting Our Families Through Addiction and Recovery (SOFAR) is an enhanced pediatric medical home model at Boston Medical Center that aims to help children thrive and mothers with SUD stay in recovery. The model integrates into one setting the many care team members necessary for supporting these vulnerable families, including primary care pediatricians, addiction-trained adult medicine providers, addiction-trained nurse prescribers, nursing-level care managers, social workers and therapists for parents, patient navigators, peer recovery coaches, and team coordinators. Children seen in the SOFAR clinic receive more frequent primary care visits than usual (weekly visits for the first month of life and monthly visits for the first year of life). Clinic staff members pay special attention to the health and developmental needs of these children, including symptoms associated with neonatal abstinence syndrome. Mothers receive co-located addiction care, primary care services, and relapse prevention services at every visit. The clinic also offers care management to help families connect with community resources, such as home visiting and parenting classes that address broader environmental and social challenges. <https://www.bmc.org/pediatrics-primary-care/sofar>

## Children Exposed to Trauma

Living in a household with drug and alcohol misuse is classified as an adverse childhood experience (ACE). ACEs are stressful and traumatic events that can lead to such a high stress response in children that it is considered toxic stress. This stress may result from an acute crisis, such as a child witnessing an overdose or death, or from living with prolonged uncertainty, anxiety, and fear. Such turmoil can take a lifetime toll on children by disrupting the development of their brains and other organs. According to the Centers for Disease Control and Prevention (CDC), ACEs have been linked to risky health behaviors, chronic health conditions (such as diabetes and obesity), limited opportunities reflected in low-academic achievement and graduation rates, and early death through suicide.<sup>11</sup> The more ACEs a child accumulates, the higher her or his risk of experiencing long-term health issues. In the short term, the symptoms of trauma may be misattributed to bad behavior, immaturity, or other developmental factors. Even children who do not express their distress may be quite aware that something is wrong, even if they are too young to give it a name.

Exposure to traumatic events, however, does not mean a child is destined to suffer the ill effects of toxic stress. Early recognition and proper intervention can reverse trauma's damaging effects. Increasing access to and the supply of licensed mental health professionals for children is important, as is expanding the number

of responsible adults who can identify children in need of help and provide them with safe, stable, and nurturing environments. First responders, such as police or emergency medical service (EMS) personnel, can play a particularly important role in identifying children who have witnessed an acute traumatic event such as an overdose. Typically, an emergency response is focused on the individual in distress, without a systematic approach to identifying the family members surrounding that person. In a personal communication to the authors, a service provider from Long Island, New York, described a child who matter-of-factly stated that his role in the family was moving the couch out of the way when EMS arrived to resuscitate his older brother. In most situations like this, children are unlikely to be identified and offered support. Schools can also play an important role in reducing the impact of trauma. Creating a trauma-sensitive school involves flexibility, staff training, links to mental health professionals, and special educational tools for some children.<sup>12</sup>

## **Handle With Care**

A child's presence during a traumatic event (such as a drug overdose or parental arrest) often goes unnoticed. Handle With Care, a collaboration between law enforcement and the school system in West Virginia, is changing that. This program, developed in West Virginia and now used in several communities across the country, aims to ensure that all children exposed to trauma receive appropriate interventions so that their ability to succeed in school is not jeopardized. Law enforcement officers at the scene use a standard protocol to notify the child's school that an incident has occurred. Before the start of the next school day, the principal receives a confidential note with the child's name that simply states that the child has been at the scene of a police incident and should be "handled with care." Teachers and other staff, all of whom have received trauma-sensitive training through the program, monitor and engage with the child in ways that are supportive and not punitive, such as postponing testing or providing calm and safe spaces for the child to recover. Additional school-based mental health services are made available to children that exhibit continued emotional or behavioral issues. At the core of the program is a recognition that trauma "turns off the learning switch" and that, unless these children are identified and helped, the cycle of trauma in families will likely continue. Funds to expand the program were included in the federal 2018 SUPPORT for Patients and Communities Act. <http://handlewithcarewv.org/index.php>

## Young Caregivers

Of all the populations at risk, the least recognized and studied group includes children and teenagers who become caregivers for others in the family—parents, siblings, grandparents, and others. In general, young caregivers take care of household tasks like shopping and preparing meals and may take on more demanding responsibilities like managing medications,<sup>13</sup> changing bandages, assisting with mobility, monitoring unsafe behavior, and much more. To date, the only national survey on young caregivers was conducted in 2005 by the National Alliance on Caregiving and UHF. The survey found an estimated 1.5 million children ages eight to 18 performing caregiving tasks similar to those performed by adults. This number is undoubtedly an underestimate because participants under the age of 18 had to obtain parental consent. Parents with substance use disorders or mental health problems were unlikely to give consent for their children to talk to researchers.<sup>14</sup>

It is likely that the opioid epidemic has increased the number of children and teenagers who are taking on adult caregiving responsibilities. Anecdotal reports suggest that some young caregivers even handle tasks directly related to SUD. One meeting participant reported that children pick up naloxone kits at a dispensing outlet in case a parent overdoses.

Other countries have taken a far more hands-on approach to young caregivers. In the United Kingdom, for example, children as young as five are counted in the census as “carers,” a British term, if they do caregiving tasks. Young carers are entitled to an assessment of their needs for support and, at age 18, are evaluated for their transition

## American Association of Caregiving Youth

The American Association of Caregiving Youth (AACY) in Palm Beach County, Florida, is the only organization solely devoted to identifying and serving youth who serve as family caregivers for a parent, sibling, or other relative. AACY defines caregiving youth as children and adolescents who are 18 years of age or younger and who provide significant or substantial assistance to relatives or household members who need help because of physical or mental illness, disability, frailty associated with aging, substance misuse, or other conditions. AACY works with the local school system, grades 6-12, to identify children struggling in school because of their caregiving responsibilities and to provide respite and support. <https://www.aacy.org/>

to adult carer services. Special support is available for these youngsters, such as peer group meetings, recreational activities, acknowledgment of their work on a National Young Carer's Day, and one-on-one counseling if needed.<sup>15</sup> A comparison of several countries' policies about young caregivers placed the United Kingdom in the lead, with the United States at the low end of the international spectrum—that is, “still emerging.” The United States was one level ahead of United Arab Emirates and Greece and just one level above the bottom, where nothing is being done.<sup>16</sup> The authors (one British and one Swiss researcher) asked: “Why is the most advanced capitalist society in the world at Level 5 in our classification?” That is a question that should stimulate discussion and action in the United States. The opioid epidemic, as terrible as it is, offers an opportunity to learn more about the impact of young people caring for others and to begin to build services that offer them a promising future.

## **Foster Care and Kinship Caregivers**

When parents are unable to care for their children due to SUD, the first recourse is often to turn to the child welfare system to find a safe placement for the child, either through kinship care or foster care.<sup>17</sup> After several years of declining numbers, foster care entries began to rise in 2012, partially fueled by increasing parental opioid use.<sup>18</sup> As of September 30, 2017, over 440,000 children were estimated to be in foster care, with over 69,000 awaiting adoption because their parents had lost all custodial rights.<sup>19</sup> The foster care system is under strain—there is a shortage of people willing to become foster parents, and in some areas, such as upstate New York, out-of-home placements are taking place far from home, in different counties or even out of state.

But that is only part of the picture. For every child formally placed in foster care (either with a relative or otherwise), 19 go to live with a family member, usually a grandparent, outside the foster care system, according to Grandparents United, an advocacy organization for kinship parents. An estimated 2.7 million children (4 percent of all children) are in these informal kinship arrangements.<sup>20, 21</sup>

All foster parents and kinship caregivers face challenges, but those connected to the formal foster care system have access to financial support, counseling, services for the children, and other benefits. Why then would a struggling grandparent not opt to become a licensed foster parent? There are many potential reasons, including a reluctance to be viewed as anything other than a family member and prior unsatisfactory encounters with the child welfare system (perhaps concerning their own children's upbringing). Some may prefer to avoid the required investigation of their home and assets and may see the monitoring of the family as intrusive.

These kinship parents—grandparents and others—need help finding available legal and financial resources as well as guidance on identifying the right support for children adjusting to the new arrangement. They are often dealing with grief and guilt as well as the stigma associated with being the parent of a person with SUD. They may need services themselves, such as navigators (who can help access financial resources), assistance in establishing legal rights to make school and medical decisions for the child, and peer support that reduces their isolation. Because children may act in ways that are stressful or self-destructive, they also need help in learning how to manage trauma in children. They may need additional health care resources for themselves.

## **Relatives As Parents Program**

The Brookdale Foundation in New Jersey founded the Relatives As Parents Program (RAPP) in 1996 to provide services to relative caregivers looking after children outside the foster care system. In the program, the primary reason for a biological parent's inability to fulfill his/her role is substance use disorder. RAPP programs help kinship guardians cope with the loss of their adult child to death or addiction, their own independence, and expectations for their future. Some needs are practical, such as legal issues and financial instability; others are emotional and physical. As part of the Foundation's sponsorship of RAPP, it conducts a national orientation and training conference to facilitate opportunities for training, networking, and information exchange. <http://www.brookdalefoundation.net/RAPP/rapp.html>



## Cross-cutting Themes and Recommendations for Action

Participants in the ripple effect meeting stressed the urgency of addressing all the problems, citing the existing strengths in agencies and programs supporting children and families, while acknowledging the challenges. Among these are lessons learned from the HIV/AIDS and crack cocaine epidemics about what to do and what not to do. There are many examples of multidisciplinary, evidence-based programs that work, but additional resources are needed to spread them and to research promising new programs. Despite the gravity of the situation and barriers to moving forward, participants at the meeting expressed a sense of hope and energy that should be encouraged and sustained.

Three breakout sessions yielded recommendations in research, policy, and practice. They are summarized here under four cross-cutting themes. Though not every good idea could be captured in this report, this agenda provides a framework for moving forward. It should be viewed as a complement to the many other well-researched agendas on how to address the general opioid epidemic, including containing its spread and improving treatment for those with SUD.

Leadership is essential. The federal government has an important role to play in funding and setting guidelines for states and local governments. But at the program and policy level, state, local, and county governments should take the lead and

### Federal Funding Sources

Several federal funding sources may be available to states and local communities to support expanding and integrating services for families affected by the opioid epidemic. These include long-standing federal sources for maternal and child health and development, like the Title V Maternal and Child Health State Block Grants and the Individuals with Disabilities Education Act. Some more recent federal opportunities include:

- Families First Prevention Services Act
- 2018 SUPPORT for Patients and Communities Act
- Child Abuse Prevention and Treatment Act (CAPTA)
- Centers for Medicare and Medicaid Innovation's MOMS and InCK demonstration projects
- Medicaid Expansion

See Appendix B for descriptions.

should engage experts in all the related fields. Government officials should also reach out to community leaders and representatives of the affected populations, such as persons recovering from SUD, kinship grandparents, and adolescents affected by the epidemic.

## **1. Reduce stigma and misunderstanding of opioid use and treatment**

Reducing stigma is necessary to identify children and families in need of support and to increase the public and political will to vigorously respond to the opioid epidemic. A sense of shame about drug use is deeply rooted in American culture, even as this crisis affects more and more people drawn into SUD through many different routes (e.g., surgery or injury recovery). Stigma surrounding opioid use is not just about drug use; it is also about treatment. Both members of the public and some medical professionals share a widely held and erroneous view that MAT is merely substituting one drug for another and that only abstinence is acceptable.

Stigma hinders an effective response to the epidemic and also directly harms children affected by familial SUD. It can deter individuals from seeking help for themselves or their family members, and high levels of stigma have been found to be associated with public support for more punitive policies toward individuals with SUD rather than public health approaches. Children themselves are not immune from these forces; they may not ask for help from teachers, coaches, or other adults because of shame or fear of being removed from the home and perhaps separated from their siblings.

### ***Recommendations***

State and local departments of health, education, and child welfare can lead an effort to reduce stigma surrounding SUD by partnering with media outlets and professional organizations in all fields that deal with children and families. Specifically, this effort should include the following actions:

- Promote the use of nonjudgmental, nonpunitive language. Examples are “person in recovery” rather than “former addict” and “person with a substance use disorder” rather than “addict,” “junkie,” or “drug seeker.” In discussions about neonatal abstinence syndrome, describe it as an expected and treatable condition rather than saying it stems from a “baby born addicted to drugs.”<sup>22</sup>
- Develop educational programs on the nature of SUD and its treatment. All who interact with children and families—including health care, education, social service, and family court professionals—should perceive substance

use disorder not as a moral failing, but as a chronic medical condition that affects a person's brain. They should understand that recovery is possible, although challenging. Professional associations and the education sector can collaborate to provide multidisciplinary, rapid trainings on what SUD is and evidence-based approaches to responding to the needs of affected families.<sup>23</sup>

- Learn how stigma was reduced for other diseases such as cancer and HIV/AIDS. Review the experience with other, once stigmatized and now accepted diseases, such as cancer and HIV/AIDS, and to some extent, dementia. What made the difference? Educating the public about the biological underpinnings of SUDs is one strategy, but an in-depth review of shifts in the public's understanding of other conditions may reveal still more factors that reduce stigma.
- Create opportunities for people affected by the opioid epidemic to tell their stories. The ripple effect is all too often hidden from public view. Programs serving these populations and media organizations can invite those affected to speak or write about their experiences, sharing not only their pain but also stories of the people and services that helped them and their families. Media stories should balance the heartrending reality of family substance use with the message that recovery is possible.

## **2. Make Investing in a Response to the Ripple Effect a Priority**

Investments in children's mental health and prevention activities at the state and federal level have not kept pace with the need. As a result, large sections of the country, especially rural areas, lack sufficient children's mental health services. Effective programs that can help children affected by, or at risk for, substance use disorder have not been scaled to the scope of the problem. When money is available, it often comes from multiple sources and involves cumbersome reporting requirements, which are difficult for community-based organizations to fulfill. Without sufficient data on the magnitude of the ripple effect and its consequences, it is difficult to convey to the public and policymakers the urgency of the issue.

These recommendations are intended to emphasize the hidden aspects of the ripple effect and make up for historical underinvestment in children and family services. Where new funding and/or policies are required, these efforts should be led by policymakers (governors, state legislatures, county and local legislative bodies). Where existing program flexibility can be leveraged, agencies should use this flexibility and inform policymakers about necessary additional resources. In both instances, government officials should pursue these efforts in close coordination with research institutions, advocacy groups, providers, and other stakeholders who can help make these recommendations a reality on the ground.

## ***Recommendations***

- Encourage integrated services for parents and children. Policymakers should set a goal of making SUD treatment and addiction recovery services more family-friendly by encouraging integration of services for parents/caregivers and children into a single setting. Examples of family-friendly integrated services include primary care models that offer pediatric physical and mental health services alongside supports for parents in recovery, adult outpatient treatment facilities that have child-care or child enrichment programs, and home-based services. To facilitate expansion of such services, policymakers should launch demonstration projects that integrate services for families in SUD treatment or recovery in one setting, train staff members at these facilities to work in a multidisciplinary context, and widely share lessons from the demonstration projects. Financial reporting and regulatory requirements should be streamlined to allow integration of services. In areas where service integration is not possible, practices should forge partnerships with community-based organizations that can deliver robust care coordination services. Providers should also offer special training on ways to include a family perspective in staff work and expectations on how to coordinate with other providers involved in the family's care.
- Increase the availability of family-based mental health services. Policymakers should expand the use of evidence-based, family-based mental health services that treat the whole family as the client. Family-based mental health services, such as Functional Family Therapy and Parent-Child Interaction Therapy, help to strengthen and maintain family relationships and improve the overall functioning of the family. Policymakers can support the spread of these services by increasing funding for them, especially as prevention services offered by child welfare programs, including them as Medicaid benefits, and increasing the supply of mental health providers trained in the dominant evidence-based models.
- Invest in evidence-based and promising prevention and intervention programs that promote youth development. Policymakers should allocate new sources of state and federal funding to widely spread and scale evidence-based programs and services, particularly those that promote the health and well-being of children and teens; these could range from broad prevention programs to highly targeted services for children in complex families. Many but not all evidence-based programs are included in the Blueprint for Healthy Youth Development database, a registry of youth development programs funded by the Annie E. Casey Foundation.
- A sum of new money should be allocated to researching promising new programs, preferably those designed with significant input from affected families.

- Provide technical assistance for implementation and evaluation. Policymakers should partner with experts in children’s health, mental health, and educational needs to establish regional or statewide resource centers of excellence to help communities implement evidence-based programs, share best practices, and research emerging models of care for families. To ensure good outcomes, service providers should use implementation science<sup>24</sup> to evaluate the adaptation of evidence-based programs and the fidelity of implementation.
- Quantify the magnitude of the ripple effect. Researchers should use both quantitative and qualitative methods to determine the extent of the ripple effect, the impact on children’s and families’ lives, and the results of the programs that serve them. These results should be disseminated widely.
- Reduce geographic and racial/ethnic disparities in access to services. Policymakers should focus on reducing racial/ethnic and geographic disparities in access to supportive services for children and families affected by SUD. Especially in rural areas, resources to establish family-centered treatment services are in short supply. African American and American Indian/Alaska Native children are already disproportionately represented in child welfare systems; increases in family preservation services and supports for foster and kinship families should aim to eliminate these inequities.<sup>25</sup>

### **3. Ensure that government and private agencies work as a team**

Even though agencies and professionals start with the same goal—ensuring the best possible outcome for children and families—they often reach different conclusions about the best path to take. Programs and government agencies each work within a distinctive culture, operating style, approach to treatment, and set of services they can offer. As one participant said at the meeting, “What door the family enters determines the way they are treated and their willingness to participate.”

Different perceptions of what constitutes risk to a child and whether and when government intervention is warranted makes it difficult for agencies to communicate effectively, leaving families wary of becoming involved with potential sources of assistance. These communication and collaboration barriers exist throughout the health care system and between different sectors, such as child welfare and health care.

Policymakers, executive branch leaders (especially governors), professional associations, health care providers, and child welfare professionals should establish a forum for candid discussions and consensus about better ways of working together.

## ***Recommendations***

Establish a coordinated prenatal and postnatal care plan for women with SUD. State commissioners, professional associations, health care providers, and child welfare agencies should establish a coordinated prenatal care system that links prenatal care, delivery, and postnatal care with SUD providers and includes programs aimed at preventing foster care placement. The goal should be to help pregnant women access MAT, create a safe plan of care for both mothers and babies, and standardize risk assessments and protocols about when to notify child protective services and when to remove a child from parental custody. This should include eliminating punitive policies that discourage women from seeking care. Pregnant women should also be given clear information about NAS and its treatment, as well as child welfare procedures.

- Emulate and expand community-based, collaborative forums to address gaps in helping families. Several communities have established cross-sector forums, such as opioid fatality review boards and RxStat (a New York City-based public health and public safety partnership) to review opioid overdoses and deaths and identify missed opportunities for interventions. These forums can be expanded to include a review of the ripple effect—not only to look at how an incident could have been avoided, but also to better understand how to help family members going forward. The results of their findings should be used to mobilize resources to fill these gaps.
- Develop comprehensive state, city, or regional plans. Ultimately, the responsibility for aligning policies and promoting collaboration between agencies serving children and families rests with the executive branch. Governors, county executives, and mayors should establish interagency task forces with an explicit mandate to develop a plan for responding to the ripple effect. The plan should include target indicators or quality measures, such as the number of treatment facilities providing child care or the number of children receiving behavioral health supports.

## **4. Identify children at risk as early as possible**

Many children affected by SUD are hidden unless there is a crisis, such as an overdose, death, arrest, or a problem directly related to the child. Policymakers and providers need to develop systems to help the many adults who interact with children recognize the signs or causes of childhood trauma and connect children to trauma-informed care. This work needs to expand well beyond traditional child health and development experts to include trusted individuals in the lives of children; first responders, teachers, coaches, family members, and parents of other children all have a role to play.

When a child is present during an emergency affecting his or her parent, first responders understandably focus their attention on the parent, who may be unconscious, dying, or already deceased. These first responders are not insensitive—they need to try to save a life if they can. But once the crisis is over, is there more they can do for the child or children? They generally have no established protocols for such situations beyond calling for child protective services or handing the child over to a family member. In addition, youth caregivers, generally teenagers, may deny problems, fearing repercussions from the parent or being removed from the home and separated from the siblings they often care for.

### ***Recommendations***

- Create protocols that help first responders identify children present at potentially traumatic events and connect them to trauma-informed care. The protocol should include both incidents (e.g., overdoses, deaths, or arrests) that happen in the community as well as in health care settings. There should be ways to identify children who may have been traumatized by the event and develop nonjudgmental, privacy-protected ways to alert schools and other community organizations about the child's need for special attention.
- Encourage schools to be trauma-informed. Communities can engage with their local school boards to develop concrete plans for helping schools in their area become trauma-informed. Efforts should include leadership by school and district administrators, professional development for all school staff, identification of necessary resources for students and staff, a review of existing school policies, the development of trauma-informed strategies, and collaboration with families. Organizations such as the Trauma and Learning Policy Initiative in Massachusetts are available to help schools and communities with this transition.
- Support kinship caregivers in identifying and responding to signs of trauma in children. Kinship caregivers, who may be traumatized themselves, require special knowledge, tools, and support to meet the social, emotional, and mental health needs of children who have lost a parent or have been removed from their homes. Resources for caregivers from entities such as Zero To Three, The National Child Traumatic Stress Network, and the Annie E. Casey Foundation are publicly available, but kinship caregivers may not know about them. Public agencies can work with these entities and local program leaders and experts to get these tools into the hands of caregivers.
- Develop quantitative and qualitative research about youth caregivers. Use qualitative interviews to learn directly from young caregivers about what they do, what they need, and what challenges they face. Use public health

survey tools like the CDC's Youth Risk Behavior Surveillance System to develop quantitative data about the demographics of this population and their responsibilities and to create educational opportunities and appropriate programs for peer support. Establish contacts with leaders in the United Kingdom to learn about their system of supports. Through an international convening, draw on the experience and knowledge of researchers, program leaders, government agencies, and charitable organizations in the United Kingdom and Canada to develop an appropriate series of activities that would be supported by federal and state funding in the United States. Although the health care and social service systems are different in these countries, the needs of these young people are universal.



## Conclusion

The effect of the opioid epidemic on families is far-reaching and, by extension, so are the recommendations in this report. As a nation, we can do more for children affected by familial substance abuse, but it will take a concerted effort and a firm resolve to confront tough problems. This report includes actions that can be taken by government, the private sector, researchers, health care and social service professionals, teachers, first responders, law enforcement agencies, and all people who interact with children and families—that means each of us in our professional capacities. But we all must also act in another capacity: as caring human beings. A big, collaborative, successful effort to reach children in the crosshairs of the opioid crisis will require as much compassion as coordination.

It will also require that we resist the powerful pull of despair. Helping these children and families is not a matter of possibility—it is a matter of priority. Once we all decide that responding to the ripple effect is a priority, we can build a bridge between what we know and what we can do.

The quotes at the beginning of this report painted a picture of the challenges we face. Let us end with a positive story. Jarrett J. Krosoczka, author of a graphic novel for teens about growing up with family addiction, wrote, “There is no changing the past. Everything that has happened, no matter how difficult, has made me the person I am today. I am now living out my childhood dreams of making a living as an author and an artist, but it is a greater triumph for me to have created a stable, loving home with my wife.”<sup>26</sup>

## Acknowledgments

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Our deepest gratitude goes to the participants of the meeting, who demonstrated over two exhilarating days their passion, expertise, and commitment to the children and families affected by the opioid epidemic, and to all children whose life circumstances and traumas make them vulnerable.

## Appendix A: Participants in the UHF Ripple Effect Meeting

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## Appendix B: Recent Federal Funding Sources

**Families First Prevention Services Act:** This new law reforms child welfare financing to allow use of federal Title IV-E (of the Social Security Act) dollars for the provision of specific services designed to prevent a child from entering foster care. Under prior law, these federal dollars could be spent only for the maintenance of a child who had been removed from the home. The services allowed are for 1) mental health and substance abuse prevention and treatment and 2) in-home parent skill-based services, including individual and family counseling. Services can be given to the child, parents, or kin caregivers of the child. The new rules take effect October 1, 2019.

**2018 SUPPORT for Patients and Communities Act:** This sweeping, bipartisan bill contains many provisions of special interest to those concerned with the impact of the opioid crisis on children and their families. Among them are provisions that provide additional funding for The Substance Abuse and Mental Health Services Administration (SAMHSA) Residential Treatment for Pregnant and Postpartum Women program and the SAMHSA National Child Traumatic Stress Initiative; a new SAMHSA grant program to establish or operate comprehensive opioid recovery centers; authorization of Department of Education grants that link educational agencies with mental health systems; funding for the Department of Health and Human Services (DHHS) to award to various entities to develop, enhance, or evaluate family-focused substance abuse prevention and treatment programs; and funding for DHHS to replicate and evaluate a “recovery coach” model project for parents with children in foster care due to parental substance abuse. The law also mandates coverage of medication-assisted treatment within state Medicaid programs.

**Child Abuse Prevention and Treatment Act (CAPTA):** CAPTA, the key federal legislation addressing child abuse and neglect, provides state grants to improve activities related to the prevention, assessment, investigation, prosecution, and treatment of child abuse and neglect. Grants for demonstration projects are also provided to community-based nonprofit organizations. In 2018, Congress authorized an additional \$60 million for states to “improve their response to infants affected by substance use disorder and their families,” directing states to prioritize development of plans of safe care for substance-exposed infants.

**Centers for Medicare and Medicaid Innovation’s InCK and MOMS demonstration projects:** In January 2019, the Centers for Medicare and Medicaid Innovation announced two Notices of Funding Opportunities for health care demonstration projects related to the opioid epidemic. Integrated Care for Kids (InCK) is a child-centered, local service delivery and state payment model aimed at improving the quality of care for children through the integration of physical,

behavioral, and other child services. The Maternal Opioid Misuse (MOM) model aims to better align and coordinate care of pregnant and postpartum Medicaid beneficiaries with opioid use disorder. Up to eight cooperative agreements will be made for the InCK model, and up to 12 cooperative agreements will be executed for the MOM model.

**Medicaid expansion:** Under the Patient Protection and Affordable Care Act, states have the option of expanding Medicaid eligibility to individuals with incomes up to 138 percent of the federal poverty level. Because Medicaid plays a major role in facilitating access to inpatient and outpatient treatment services for individuals with opioid addiction, as well as physical and mental health services for children, non-expansion states can improve access to preventive services and treatment by expanding Medicaid.

## Appendix C: For Further Reading

There is a fast-growing body of literature, both professional and in the media, that looks at the impact of the opioid epidemic on children, adolescents, and families. We have selected several publications that address the topics covered in this report.

### Overviews of the Epidemic

Sederer, L, M.D. October 2017. “America’s Opioid Epidemic.” Scattergood Foundation, Philadelphia, PA. <https://www.scattergoodfoundation.org/publication/americas-opioid-epidemic/?previous=7>. A report on the opioid epidemic that covers barriers, solutions (prevention, treatment, and policy), and advocacy. Dr. Sederer is Chief Medical Officer of the New York State Office of Mental Health. He has also written about his own experience with pain and opioids following extensive spinal reconstruction, a piece found at <https://ps.psychiatryonline.org/doi/10.1176/appi.ps.691002>.

American Academy of Family Physicians, et al. June 2018. “Addressing the Opioid Epidemic: Joint principles of the following organizations representing front-line physicians: American Academy of Family Physicians, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American College of Physicians, American Osteopathic Association, American Psychiatric Association.” <https://www.aafp.org/dam/AAFP/documents/advocacy/prevention/risk/ST-AddressingOpioidEpidemic-061118.pdf>.

Macy, Beth. *Dopesick: Dealers, Doctors, and the Drug Company that Addicted America*. Little, Brown, 2018. A journalist’s account of the impact of the introduction of Oxycontin on rural Virginia and the efforts of concerned health care professionals to stem the tide.

New York State Office of Alcohol and Substance Abuse Services. “Reversing the Stigma.” Documentary showing people in various stages of recovery. <https://youtube.com/watch?v=7nt4dkikWoM>. Also available in a five-part series starting at: <https://www.youtube.com/watch?v=7nt4dkikWoM>.

### Overviews of the Impact on Children and Families

National Institute for Children’s Health Quality. 2018. “Insights: Treating the Opioid Epidemic as a Children’s Health Crisis.” <https://www.nichq.org/insight/treating-opioid-epidemic-childrens-health-crisis>.

Levine C. January 2, 2018. “The statistics don’t capture the opioid epidemic’s impact on children.” STAT (website). <https://www.statnews.com/2018/01/02/opioid-epidemic-impact-children/>.



Normile, B., Hanlon C, Eichner H. September 2018. “State Strategies to Meet the Needs of Young Children and Families Affected by the Opioid Crisis.” National Academy for State Health Policy. <https://nashp.org/wp-content/uploads/2018/09/Children-and-Opioid-Epidemic-1.pdf>.

## **Pregnant Women, Neonatal Substance Abuse, and Women’s Health**

Haight S, Ko J, Tong V, Bohm M, Callaghan W. (2018). Opioid Use Disorder Documented at Delivery Hospitalization—United States, 1999–2014. Morbidity and Mortality Weekly Report, 67(31), 845. [https://www.cdc.gov/mmwr/volumes/67/wr/mm6731a1.htm?s\\_cid=mm6731a1\\_w#contribAff](https://www.cdc.gov/mmwr/volumes/67/wr/mm6731a1.htm?s_cid=mm6731a1_w#contribAff).

Moore J, Bateman B, and Patrick S. May 1, 2018. Opioid Crisis in Medicaid: Saving Mothers and Babies. Health Affairs blog. <https://www.healthaffairs.org/doi/10.1377/hblog20180426.63403/full/>.

Mazure, C. M., & Fiellin, D. A. (2018). Women and opioids: something different is happening here. *The Lancet* 392(10141): 9-11. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)31203-0/abstract](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)31203-0/abstract).

## **The Opioid Epidemic and the Child Welfare System**

Radel L, Baldwin M, Crouse G, Ghertner R, and Waters A. March 7, 2018. ASPE Research Brief: Substance Use, the Opioid Epidemic, and the Child Welfare System: Key Findings from a Mixed Methods Study. <https://aspe.hhs.gov/system/files/pdf/258836/SubstanceUseChildWelfareOverview.pdf>.

Chiqué E, Strach P, and Zuber K. August 8, 2018. “Stories from Sullivan: The Other Family Separation Crisis.” The Rockefeller Institute. Albany, NY. <http://rockinst.org/blog/stories-from-sullivan-the-other-family-separation-crisis/>. The focus of this report is the impact on foster care in a rural New York State county based on on-the-ground reporting. The other reports in the series are available at <https://rockinst.org/stories-from-sullivan/>.

## **Voices of Teens Affected by Parental Substance Abuse Disorder**

Lightle, A. December 26, 2017. Heroin's Children: My life inside the US opioid crisis. Al Jazeera. <https://www.aljazeera.com/indepth/features/heroin-children-life-opioid-crisis-171030083501156.html>. An account by an Ohio teenager about dealing with her parents' substance abuse.

Krosoczka J. Hey, Kiddo. Graphix 2018. A graphic novel by a young cartoonist about growing up with a mother who has substance use disorder. Recommended for ages 12 and up.

## **Children as Caregivers**

Levine C. August 2017. "More Than 1 Million Young Caregivers Live In the United States, But Policies Supporting Them Are Still 'Emerging'." Health Affairs blog. <https://www.healthaffairs.org/doi/10.1377/hblog20170807.061390/full/>.

## **Kinship and Foster Caregivers**

Generations United. Updated 2018. Raising the Children of the Opioid Epidemic: Solutions and Support for Grandfamilies. Washington DC: 2018. <https://www.gu.org/app/uploads/2018/09/Grandfamilies-Report-SOGF-Updated.pdf>.

Henig R. June 1, 2018. The age of grandparents is made of many tragedies. The Atlantic. <https://www.theatlantic.com/family/archive/2018/06/this-is-the-age-of-grandparents/561527/>.

## **Books for Children**

Gianfortune D and Rommel K. "We Are Rising Stars: A Book Just for Kids." <https://www.amazon.com/We-Are-Rising-Stars-Book/dp/069212800X>. An art therapy book designed for children, ages 5-8 years old, affected by familial opioid use.

## Endnotes

<sup>1</sup> We use the term “epidemic,” which in its original formulation referred to diseases spread by an infectious agent but now often refers to conditions that have behavioral, genetic, or psychosocial origins, such as obesity and Alzheimer’s disease. The term “pandemic” has been proposed to describe the state of the crisis, but that refers to a worldwide spread, such as the 1918 flu pandemic, which so far has not happened. “Endemic” refers to a condition that has a constant level in a community and neither rises nor falls dramatically.

<sup>2</sup> Opioid Use Disorder (OUD) is used to specifically describe individuals with a problematic pattern of opioid use leading to clinically significant impairment or distress. We have chosen to use the broader term “substance use disorder” (SUD) in this paper to acknowledge that individuals with OUD may also use other non-opioid substances, and that many of the challenges facing families affected by the current opioid epidemic—and the proposed recommendations—apply more generally to SUD.

<sup>3</sup> Hedegaard H, Minimo A, and Warner M. Drug Overdose Deaths in the United States, 1999-2017. NCHS Data Brief, No. 329. <https://www.cdc.gov/nchs/data/databriefs/db329-h.pdf>.

<sup>4</sup> Mazure C and Fiellin D. July 7, 2018. Women and opioids: something different is happening here. *The Lancet* 392 (10141): 9-11.

<sup>5</sup> MAT includes behavioral therapy along with drugs such as naltrexone and buprenorphine, which block the effects of opioids.

<sup>6</sup> Radel R, Baldwin M, Crouse G, Ghertner R, and Waters A. November 2018. Medication-Assisted Treatment for Opioid Use Disorder in the Child Welfare Context: Challenges and Opportunities. ASPE Research Brief. <https://aspe.hhs.gov/pdf-report/medication-assisted-treatment-opioid-use-disorder-child-welfare-context-challenges-and-opportunities>.

<sup>7</sup> Moore J, Bateman B., and Patrick S. May 1, 2018. Opioid Crisis in Medicaid: Saving Mothers and Babies. *Health Affairs* blog. <https://www.healthaffairs.org/doi/10.1377/hblog20180426.63403/full/>.

<sup>8</sup> Brown JD, Vartivarian S, Alderks CE. October 2011. Child care in outpatient substance abuse treatment facilities for women: findings from the 2008 National Survey of substance Abuse Treatment Services. *The Journal of Behavioral Health Services & Research* 38(4):478-87. <https://www.ncbi.nlm.nih.gov/pubmed/21293975>.

- <sup>9</sup> Center on the Developing Child at Harvard University. 2015. Supportive Relationships and Active Skill-Building Strengthen the Foundations of Resilience: Working Paper No. 13. <https://developingchild.harvard.edu/>.
- <sup>10</sup> Schiff DM et al. August 2018. Fatal and Nonfatal Overdose Among Pregnant and Postpartum Women in Massachusetts. *Obstetrics & Gynecology* 132(2):466-474. <https://www.ncbi.nlm.nih.gov/pubmed/29995730>.
- <sup>11</sup> Centers for Disease Control and Prevention. Adverse Childhood Experiences. [https://www.cdc.gov/violenceprevention/acestudy/about\\_ace.html](https://www.cdc.gov/violenceprevention/acestudy/about_ace.html)
- <sup>12</sup> Massachusetts Advocates for Children and Harvard Law School. Helping Traumatized Children Learn: Creating and Advocating for Trauma-Sensitive Schools. <https://traumasensitiveschools.org/tlpi-publications/download-a-free-copy-of-a-guide-to-creating-trauma-sensitive-schools/>. See also: Massachusetts Advocates for Children, Harvard Law School, and The Task Force on Children Affected by Domestic Violence. 2013. Helping Traumatized Children Learn. <https://traumasensitiveschools.org/wp-content/uploads/2013/06/Helping-Traumatized-Children-Learn.pdf>.
- <sup>13</sup> Nichols M, Siskowski C, Lebron C, and Belkowitz B. December 2018. Medication Administration by Caregiving Youth: An Inside Look at How Adolescents Manage Medications for Family Members. *Journal of Adolescent Health*, 69: 33-43. <https://www.sciencedirect.com/science/article/pii/S0140197118301660?via%3Dihub>.
- <sup>14</sup> National Alliance on Caregiving and United Hospital Fund. (September 2005). Young Caregivers in the U.S. Findings from a Survey. <http://www.caregiving.org/data/youngcaregivers.pdf>
- <sup>15</sup> Carers Tust. About Young Caregivers. <https://carers.org/about-us/about-young-carers>.
- <sup>16</sup> Levine C. August 2017. More Than One Million Young Caregivers in the U.S., but Policies are Still ‘Emerging’. *Health Affairs* blog. <https://www.healthaffairs.org/do/10.1377/hblog20170807.061390/full/>
- <sup>17</sup> According to the U.S. Children’s Bureau, there are four types of kinship care. The two most common are formal kinship care, in which relatives are certified as foster parents but the child welfare agency has legal custody; and informal kinship care, in which relatives take over the child’s care without any involvement of a child welfare agency or juvenile court. There are also two other variations: voluntary kinship care, in which relatives provide care and a child welfare agency is involved

but does not have legal custody; and temporary guardianship, which could be used when a parent enters an inpatient drug treatment program. The options discussed in this section are formal and informal kinship care. U.S. Children's Bureau. (May 2016). Child Welfare Information Gateway. Kinship Caregivers and the Child Welfare System. Factsheets for Families. <https://www.childwelfare.gov/pubs/f-kinshi/>.

- <sup>18</sup> Ghertner R et al. The Relationship Between Substance Use Indicators and Child Welfare Caseloads. ASPE Research Brief. <https://aspe.hhs.gov/system/files/pdf/258831/SubstanceUseCWCaseloads.pdf>
- <sup>19</sup> U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau. The AFCARS Report. <https://www.acf.hhs.gov/sites/default/files/cb/afcarsreport25.pdf>.
- <sup>20</sup> Grandparents United. (Updated 2018). Raising the Children of the Opioid Epidemic: Solutions and Supports for Grandfamilies. The State of Grandfamilies in America Annual Report. <https://www.gu.org/resources/the-state-of-grandfamilies-in-america-2016/>
- <sup>21</sup> 2009-2018 Current Population Survey Annual Social and Economic Supplement (CPS ASEC). Estimates represent a three-year average.
- <sup>22</sup> Recovery Research Institute. Words Matter: How we describe individuals with substance problems affects perceptions. <https://www.recoveryanswers.org/research-post/how-we-describe-individuals-substance-problems-affects-perceptions/>.
- <sup>23</sup> New York State Office of Alcohol and Substance Abuse. <https://youtu.be/gnp1sjUdCkM>.
- <sup>24</sup> Bauer M, et al. 2015. An Introduction to Implementation Science for the Non-Specialist. *BMC Psychology*, 3(1): 32. doi: 10.1186/s40359-015-0089-9.
- <sup>25</sup> Citrin A and Reeves R. November 29, 2018. "Two Communities Take on Big Challenges: Local Efforts to Advance Equity in Child Welfare." Center for the Study of Social Policy. <https://cssp.org/2018/11/two-communities-taking-on-big-challenges-local-efforts-to-advance-equity-in-child-welfare/>
- <sup>26</sup> Krosoczka, J. 2018. "Hey, Kiddo: How I Lost My Mother, Found My Father, and Dealt with Family Addiction." Graphix. An Imprint of Scholastic, Author's Note, no page number.

