

Expecting Better

Improving Health and Rights for
Pregnant Women Who Use Drugs



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Acknowledgments

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For more information contact:

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Drug use in pregnancy can lead to serious health risks for both the mother and the fetus, including HIV infection and fatal overdose. At the same time, drug use during pregnancy need not lead to any negative outcomes, or to outcomes significantly different from those experienced by non drug-using women.

Unfortunately, pregnant women who use drugs face highly stigmatizing and inaccurate perceptions from both health care providers and the public at large, negatively impacting the quality of their care and supportive services. This publication seeks to move beyond the myths and anxieties about drug use during pregnancy to recommend simple approaches to benefit and protect the health of both pregnant women and newborns. These lessons are being learned across the globe: a growing number of countries, including Australia, Canada, Romania, Ukraine, and the United Kingdom, and institutions and agencies such as the World Health Organization have updated their protocols to reflect the understanding that drug use in pregnancy is not a “moral failing” and need not necessarily lead to bad health outcomes.¹ Common to effective approaches is a commitment to prioritizing access to supportive, nonjudgmental care respectful of women’s rights and choices over interventions that emphasize control and punishment, or deny women an opportunity to participate in decisions affecting their lives and that of their families.

Based on review of national and international practice and evidence, the principles described here can help those seeking to improve policies and practices that affect pregnant women who use drugs.

Author’s Note

This publication is largely based on the research and practice of health care for pregnant cisgender women who use drugs. However, there are experiences and lessons learned here that are applicable to all pregnant people.

Sharon Stancliff, MD, Kimberly Sue, MD, PhD, and Bruce Trigg, MD, have reviewed the information presented in this document for medical accuracy. However, this information should not be considered medical advice for health care providers, counselors, nurses or other professionals directly involved in the clinical care for women who use drugs, and is not a substitute for individualized patient or client care and treatment decisions. Please consult a medical professional for such advice.



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“It is impossible for babies to be born addicted. This language is stigmatizing and incorrect. Please challenge anyone who uses this terminology.”

Loretta Finnegan, MD⁶

Combat Misinformation with Facts

Few behaviors by women are as stigmatized as using drugs while pregnant. Across cultures and religions, women who use drugs and become pregnant are portrayed as unfit or irresponsible mothers. Media reporting on this issue, too often leans toward the sensational. Images of babies experiencing opioid withdrawal symptoms emphasize their suffering and suggest, inaccurately, that they will experience long-term harm. In the United States, during the 1980s and 1990s, media reports of “crack babies” implied that children born to mothers who used crack cocaine were permanently damaged.

Research shows that media claims of developmental harm to the fetus from prenatal drug exposure—whether legal and illegal—are greatly exaggerated. In contrast, environmental



factors such as social isolation, poverty, food insecurity, and lack of access to quality health care can have a greater impact on the health of a baby than prenatal exposure to drugs.²

In a systematic review of 200 studies on children exposed to opioids *in utero*, findings indicated “no significant impairments in cognitive, psychomotor or observed behavioral outcomes for chronic intrauterine exposed infants and preschool children.”³ Exposure to opioids in utero can have short-term health implications after birth—primarily withdrawal symptoms, also called “neonatal abstinence syndrome” or “neonatal opioid withdrawal.” These withdrawal symptoms are also associated with medically prescribed treatment for opioid dependence during pregnancy, such as methadone and buprenorphine.⁴ Contrary to much media coverage, neonatal abstinence syndrome is a short-term and easily treatable condition that does not have a lasting impact.

Similarly, claims about so-called “crack babies” suffering from long-term developmental delay lacked evidence and were proven to be largely driven by racist stereotypes rather than facts. The brain-damaged “crack baby” was a myth: A recent systematic review following cocaine prenatal exposure found “no consistent negative association between prenatal cocaine exposure and physical growth, developmental test scores, or receptive or expressive language.”⁵

It is also medically inaccurate to report any prenatally drug-exposed infant as “born addicted.” Addiction is defined as a set of behaviors that includes seeking opioids or other drugs despite negative social consequences, a description clearly inapplicable to infants. By disregarding the distinction between dependence and addiction, and ignoring the short-term nature of neonatal withdrawal, media hype perpetuates stigma, misinformation and punitive measures—such as mandatory drug testing and removal of children from parental care. Stigmatizing and punitive responses can discourage women from seeking evidence-based treatment and support. Advocates can help steer public conversation toward a discussion that is informed by the evidence and moves beyond scaremongering and stigma.

“Drug enforcement policies that deter women from seeking prenatal care are contrary to the welfare of the mother and fetus. Incarceration and the threat of incarceration have proved to be ineffective in reducing the incidence of alcohol or drug abuse.”

Committee opinion from
The American College of
Obstetrics and Gynecologists¹⁵

Do Not Criminalize Pregnant Women Who Use Drugs

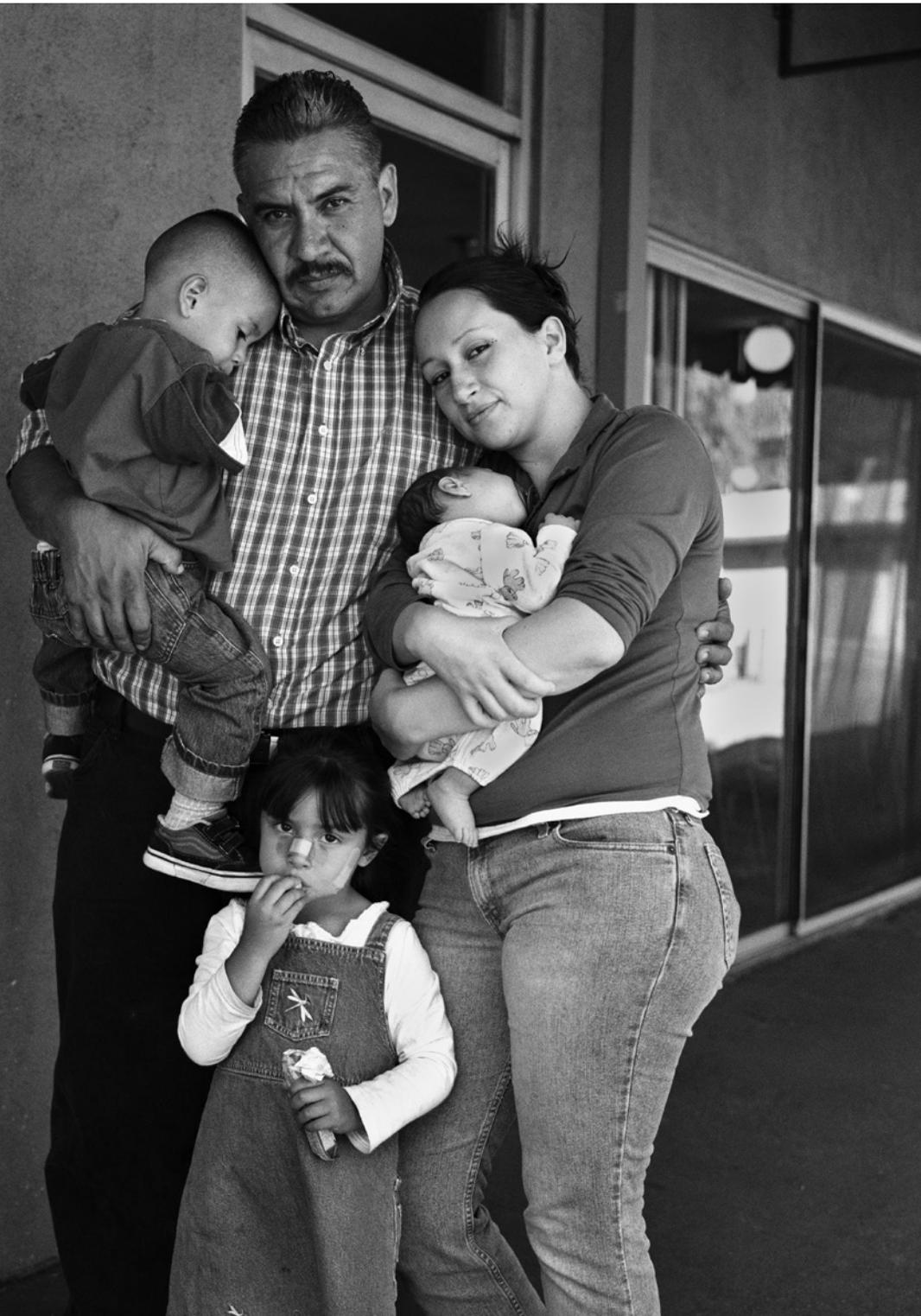
It is critical that pregnant women not face criminal charges, incarceration, and/or removal of their babies simply for the fact of drug use.

In the United States, for example, the state of Tennessee made drug use in pregnancy a crime of “fetal assault,” resulting in incarceration of some pregnant women and new mothers for up to 15 years. The law, widely criticized by health care professionals, expired in 2016.⁷ Since 1973, at least 45 states in the United States have sought prosecution for prenatal drug use under a wide variety of charges such as child endangerment, abuse, or neglect, and even manslaughter and second-degree murder if a pregnancy ends in a miscarriage.⁸ Ostensibly aimed at protecting the fetus, in reality these charges may endanger newborns and mothers alike, leading drug using women to avoid prenatal care and drug dependence treatment—two things that may actually have the most positive impact on the health of the baby and the mother.⁹

The claim that criminalization or other sanctions such as removal of parental rights can be an effective way to deter drug use is unsupported by evidence. Fear of arrest or loss of parental rights, however, has been shown to weaken the relationship between pregnant women and health care providers, especially when the providers are legally obligated to report drug use to law enforcement or child protection agencies.¹⁰ In the United States, states with laws that permit child abuse charges for drug use in pregnancy have fewer women enrolled in evidence-based drug treatment than states that do not have such laws.¹¹ Furthermore, criminalizing pregnant women fails to address common social factors that are often associated with drug use such as poverty, intimate partner violence, or previous trauma. In Norway, pregnant women who continue to use drugs can be forcibly detained in a residential facility, without consent, for the duration of their pregnancy¹² while other services available to people who inject drugs, such as access to a medically supervised site to inject drugs, are unavailable to pregnant women.

There are many major public health organizations and national health authorities that oppose using criminal sanctions to address drug use during pregnancy. World

Health Organization guidelines list “risk of incarceration/ loss of infant in punitive systems” among harms to be avoided.¹³ Similarly, the American College of Obstetricians and Gynecologists issued an explicit statement against applying punitive drug enforcement policies to pregnant women, and called instead for appropriate public health interventions based on science and evidence.¹⁴



Respect Confidentiality and Ensure Informed Consent

“The drug user registry [in Russia] could be sufficient grounds to deprive or limit a person’s parental rights. This has had an especially profound negative effect on pregnant women who use drugs, who avoid contact with the health care system for fear of losing their parental rights, including child custody.”

Mikhail Golichenko and Sandra Ka Hon Chu, researchers and advocates for the Canadian HIV/AIDS Legal Network²³

Honest discussion between health providers and pregnant women about their drug use can increase their chances to receive information, care, and support that will benefit their health and that of their newborns. Unfortunately, disclosure of drug use also makes women vulnerable to discrimination and increased scrutiny by law enforcement or child protection agencies, a risk particularly high for minority and poor women. In Georgia, Russia, and Ukraine, people who use drugs are required to register as a “drug user” when they seek drug treatment through the public system, which can lead to termination of parental rights.¹⁶ In Ukraine, despite HIV privacy laws, women report having their HIV and drug use status disclosed by health providers, leading to denial of health services, and humiliating and abusive treatment by medical staff.¹⁷ In the United States, a Florida study showed that while white and black women had equal rates of drug use in pregnancy, black women were 10 times more likely to be reported to government health authorities for their drug use.¹⁸ Similarly, drug testing without informed consent is often applied selectively, disproportionately impacting poor women and women of color using government-funded health care.¹⁹

Even if women are informed about drug tests and their potential consequences, they do not always have the power to refuse.

The World Health Organization recognizes the right to confidentiality and informed consent as the “fundamental right of all health care users.”²⁰ International and national experts agree that informed consent is key to fostering the climate of trust, respect, and collaboration between the health provider and pregnant women,^{21,22} and that advocates and health providers have a role to play in advancing policies and practices that respect women’s autonomy and dignity.



Ensure Access to Harm Reduction Services

Implementing a harm reduction approach for pregnant women who use drugs is based on an understanding that drug use is just one of the factors that shape a pregnancy, and that improvements beside abstinence from all criminalized drug use can have a positive effect on the woman's health and that of her fetus or newborn.

While abstaining from criminalized drugs is the best way to protect oneself and a fetus from drug-related harm, health improvement does not require cessation of drug use. Women can reduce the amount or frequency of drug use, learn how to use drugs more safely to prevent HIV, hepatitis C or overdose,²⁴ and take other steps to protect their health. A harm reduction approach for service providers means being willing to discuss goals other than abstinence, such as improving housing, nutrition, regularity of prenatal care, and safety, all of which are crucial for a healthy pregnancy.²⁵ This is both pragmatic and effective. Denying prenatal and other health services to a woman who is pregnant and using drugs will increase the harm, not reduce it.²⁶

Many women who use drugs come in contact with harm reduction services in their community before they try to access mainstream health care. Services, such as needle and syringe programs, or street-based outreach nursing, can provide a friendly, nonjudgmental and supportive environment, where women might be more comfortable to disclose their drug use, receive counseling, and connect to friendly prenatal care and drug treatment providers.²⁷ Harm reduction programs can also provide supports, including peer support, to help break social isolation that some women who use drugs face, particularly women who have been recently incarcerated or migrant women.

Despite being “low threshold,” in some communities harm reduction programs might be difficult for women to access. Cuts in funding have made harm reduction services less available in many middle-income countries,²⁸ particularly for women. In many contexts, existing services lack tailored, women-specific interventions.²⁹ This can create unsafe or unwelcoming environments for women, particularly in societies with traditional gender roles, like Georgia, where only 2 percent of people engaging in harm reduction are women, but where women using drugs are

Harm reduction programs can take a number of steps to meet the needs of pregnant women. Some examples include:

- Ensure access of pregnant women to all available evidence-based harm reduction services by creating a safe and welcoming environment. This might include women-only safe spaces, mobile services that can meet women where they are, and having more women on staff.
- Repeal regulations barring pregnant women from use of medically supervised injection facilities.
- Offer free pregnancy tests, baby supplies, and childcare.
- Offer empowerment and education to address intimate partner violence and provide access to legal aid, including on issues of parental rights and custody.
- Foster links to non-judgmental pre- and postnatal health care, counseling services, employment, education, housing, or other resources within the community.

often “second on the needle” and so at greater risk of blood-borne infection.^{30,31} Additionally, pregnant women may avoid services because they face especially severe stigma and judgment from other service users. Few harm reduction programs offer pregnancy tests, childcare, or cover transportation costs,³² while women who use drugs usually bear the bulk of caretaking responsibilities and are more likely to live in poverty.³³

Programs might also explicitly prevent pregnant women from access. In Denmark, where a full range of harm reduction interventions are available to those who need them, pregnant women are the only group who are expressly excluded from supervised drug consumption facilities and heroin treatment programs despite evidence that these interventions are effective in preventing overdose and reducing other adverse consequences of injection.³⁴ By contrast, similar programs in Vancouver, Canada, do not deny access to pregnant women, recognizing them as clients who stand most to benefit from these interventions.³⁵

Increasing availability and accessibility of harm reduction services for women can increase opportunities for engaging pregnant women who use drugs in care and provide a point of entry for prenatal care and treatment.

“I’ve had both of my babies while taking buprenorphine and they are both happy and healthy.”

Anonymous participant in a buprenorphine consumer listening session⁴²

Facilitate Access to Methadone and Buprenorphine

Detoxification from all opioids carries significant health risks for pregnant women who are dependent on opioids,³⁶ yet misinformed providers often persuade women to cease all opioid use during pregnancy. In some cases, the provider may reprimand or otherwise seek to punish a woman if she refuses to follow the provider’s enforced abstinence-only treatment. Pregnancy is the time when many women who use drugs have the greatest chance to benefit from access to supportive care, including engaging in opioid dependence treatment with the medications methadone or buprenorphine. Many international guidelines such as those from the World Health Organization, UNAIDS, and the UN Office on Drugs and Crime, recommend methadone or buprenorphine as the most effective and safe treatment options for people with problematic opioid dependencies and these medicines are approved for women using heroin or other opioids during and after pregnancy.³⁷ As with any medications, methadone and buprenorphine are associated with some risks; however, research shows that the benefits of these medicines far outweigh the associated risks in pregnancy, and that their use is safer than attempting cessation of all opioid use.³⁸ Instead of a pregnant woman becoming sick with withdrawal symptoms and then engaging in risky behaviors to obtain unregulated drugs, use of legally prescribed methadone or buprenorphine can provide physical relief and stability. This stability protects the health of the mother and her fetus as well as opens up opportunities to connect women to care and supportive services. Methadone or buprenorphine can be combined with social work and other comprehensive care (i.e., stable housing, nutrition education, counseling, additional health care).³⁹ As previously noted, while methadone and buprenorphine can cause temporary neonatal abstinence syndrome symptoms for the baby after birth, these symptoms are treatable and nonlife-threatening.⁴⁰ It is recommended that methadone or buprenorphine be continued during the postpartum period to reduce the risk of returning to problematic opioid use and experiencing a potential overdose.⁴¹

It is important that pregnant women are informed of all available treatment options in their communities. Ultimately, a woman’s own decision on whether to use any of the treatment options must be respected and supported.



Ensure Access to Adequate Pain Relief during Labor

“I was never offered pain medications during any of my pregnancies. I even broke my arm while on buprenorphine and the doctor assumed I was just ‘drug seeking.’”

Anonymous participant at a New York City harm reduction program⁴⁹

Many women require access to adequate pain management in childbirth, and women who use drugs are no exception. Rather than being offered supportive care during labor and delivery—an incredibly stressful time for any woman—women who use drugs may receive substandard medical care. Women who use drugs might have barriers in accessing pain relief during and after labor for a number of reasons including the common discriminatory suspicion that people who use drugs are just “seeking drugs.” For women who are opioid dependent, anticipated anxieties can be associated with problematic intravenous access and inadequate pain management.⁴³ Additionally, there is evidence that stigmatizing beliefs and practices among health care providers often yield negative health outcomes for patients with known drug use.⁴⁴

Existing research shows that pain can be successfully managed in women who are dependent on opioids during labor and delivery.⁴⁵ There is no evidence that exposure to pain-relieving medications during childbirth increases risks of problematic drug use after delivery in pregnant women who had used drugs and stopped prior to pregnancy or delivery. Without proper pain management, intensive pain during labor and delivery can lead to long-term physical, psychological, and emotional impacts for the mother.⁴⁶ For pregnant women who are opioid dependent, denial of or inappropriate pain management can lead to return to criminalized drug use.⁴⁷ Discussing pain management options with pregnant women early in pregnancy can be one way to foster a relationship of trust and support between the prenatal care provider and the woman to strengthen the woman’s motivation to stay engaged in care.⁴⁸

Support Women through Birth and After

After a woman who uses drugs gives birth, some countries immediately separate the mother and baby in order to place the baby in an intensive medical care unit for observation. Immediate separation can also occur in countries in which a woman faces arrest or detention for drug use during her pregnancy. Childbirth, a time that can be filled with joy and love, suddenly becomes incredibly stressful for mothers who may suffer feelings of deep shame and sadness from the sudden, enforced separation. Again, harsh judgments from care providers and exaggerated misconceptions about drug use during pregnancy make this worse. Well-meaning providers often believe they are “protecting” the baby by this separation, when in fact, mounting research recommends the importance of supportive bonding after birth, including for mothers who used drugs.

Skin-to-skin physical contact or “rooming-in” after birth has many benefits for mothers and their newborns.⁵⁰ For a woman who used drugs during her pregnancy, encouraging skin-to-skin contact, including aiding in breastfeeding, has the potential to improve the mother’s motivation to decrease problematic drug use and seek treatment.⁵¹ In addition, allowing opportunities for physical bonding after birth can erode certain misconceptions about the mother’s caregiver capabilities and build trust with her providers. In a systematic review of the best practices for babies exposed to opioids during pregnancy, recommendations included maintaining physical contact in a low stimulation environment (e.g., dim lighting) through breastfeeding, swaddling, massage, and cuddling.⁵² Research shows that immediate, forced separation could cause further emotional trauma for the vulnerable mother and even increase symptoms of neonatal abstinence syndrome in babies who are opiate dependent.⁵³

“As soon as a woman who is using [drugs] gets pregnant, society often forgets about her and focuses on keeping the baby safe, but we must remember and understand that the mother and baby are a dyad and must be treated as a unit.”

Outreach nurse
in Vancouver’s
Lower Eastside⁵⁴

Connect Women to Domestic Violence Services When Necessary

Women who use drugs often experience physical, sexual, and emotional violence and abuse. While violence from an intimate partner is common, women who use drugs can also experience violence from sex work clients, law enforcement officers, suppliers of unregulated drugs, family members, or peers. In many cases, women depend on their abusive partners for housing, drugs or income and may risk becoming homeless if they leave. Women who experience violence are at increased risk of being a victim of homicide, preterm labor, miscarriage, and other obstetric complications.⁵⁵ Intimate partner violence can also hinder the negotiation of condom use and increase risk of HIV. Research suggests that women with a history of experiencing violence are more likely to continue drug use as a way to self-medicate and cope with the trauma.⁵⁶

Because drug use is both incredibly stigmatized and criminalized in many countries, there are significant barriers for pregnant women to seek support when facing violence. Many antiviolence programs or shelters do not admit women who are active drug users, claiming they do not have the capacity to help, while harm reduction services rarely address issues of violence explicitly.⁵⁷ Advocacy to make domestic violence shelters open to pregnant women who use drugs is crucial to improving their safety. Fostering connections and coordination among antiviolence services and harm reduction programs has the potential to reduce significant barriers to timely access to health care and other services.

Make It Easier to Navigate Health and Social Services

A pregnant woman who uses drugs may need a variety of services offered by different providers, including an obstetrician, midwife, social worker, drug treatment provider, and many others. Globally, there are few health and social services systems that provide integrated and coordinated care for pregnant women who use drugs. In most cases, the burden of navigating a complex system, where many providers are located in different parts of town or require different documentation, is on women who are already in stressful situations. This burden only increases if a woman also has to address legal issues or challenges related to child custody.

A comprehensive, coordinated approach is essential to provide optimal care for pregnant women who use drugs. One way to strengthen coordination is to involve managers trained in harm reduction who can liaise with the many different types of services. Evidence shows that community-based case management services for women who use drugs can significantly improve women's ability to stay engaged in supportive care and treatment.⁵⁸



Introduce National Guidelines Based on Evidence and Respect for Human Rights

National clinical guidelines, based on rigorously researched evidence, human rights standards, and respect for confidentiality, are an important way to ensure that pregnant women who use drugs can access the care they need without stigma or discrimination.

Guidelines are a set of practical recommendations, frequently issued by the national health authority, for all health and social service providers who are involved in caring for pregnant women who use drugs and their children. The guidelines are usually developed by a collective of experts and practitioners, who review existing clinical evidence and best practices, and recommend each intervention based on the strength of this evidence. The guidelines also set out key goals in providing care, designate responsible providers, and describe underlying principles and values. Once adopted, the guidelines serve as standards of care against which providers can be held accountable for violations or for failing to provide the expected quality of care.

In 2014, when the World Health Organization introduced the first global evidence-based recommendations on managing pregnancy and drug use, only a handful of countries had national guidelines covering these issues.⁵⁹ Today, countries including Australia and Canada have also articulated guidelines, though many countries have yet to do so.

The existing international and national guidelines share several important points:

- They aim to “safeguard against stigma and discrimination” and recognize that women should have a voice and autonomy in decisions about treatment options. (World Health Organization)⁶⁰
- They prioritize establishing a “trusting and empathetic relationship in which the women will feel encouraged to continue pregnancy care.” (Australia)⁶¹
- They emphasize the importance of informed consent, particularly for interventions, such as drug testing, that might negatively impact women’s legal rights. (Canada)⁶²
- They integrate harm reduction approaches for pregnant women, despite continued drug use. (UNODC)⁶³

- They prioritize evidence-based information over moralistic attitudes. (European Monitoring Centre for Drugs and Drug Addiction)⁶⁴
- They recognize the mother and infant as a dyad to “optimize the outcomes for the mother–infant dyad as a whole.” (United States)⁶⁵

While introducing a set of recommendations at the national level is the first step toward improving care available to pregnant women who use drugs, it is not the last one. Civil society has a role to play in ensuring that the guidelines actually work: that the providers are trained and have resources to implement them; that violations are monitored and reported; and that recommendations are regularly reviewed and updated based on the latest evidence.



Selected Resources for Advocates

View the electronic version of this report at osf.to/expectingbetter for hyperlink access to these resources.

Women Who Use Drugs, Harm Reduction and HIV⁶⁶

An issue brief developed by advocates and women with lived experience of drug use. It highlights several gender-specific challenges in harm reduction and offers an overview of recommendations for national and international programmatic and policy interventions.

Women Speak Out: Understanding Women Who Inject Drugs in Indonesia⁶⁷

Findings from a participatory research study among women who use drugs in Indonesia, including programmatic and policy recommendations.

Pregnant Women and Substance Use: Overview of Research & Policy in the United States⁶⁸

A United States-based set of policy recommendations focusing on the health and human rights of pregnant women who use drugs that highlights the history and consequences of stigma and racial discrimination.

Harm Reduction and Pregnancy: Community-based Approaches to Prenatal Substance Use in Western Canada⁶⁹

A booklet that defines several harm reduction approaches for the population of pregnant women and offers examples of several best practice programs in Western Canada.

Making Harm Reduction Work for Women⁷⁰

A summary of findings from a needs assessment and recommendations for implementing gender-responsive harm reduction for women in Ukraine.

By Women, For Women: New Approaches to Harm Reduction in Russia⁷¹

A summary of findings from a needs assessment and recommendations for implementing gender-responsive harm reduction for women in Russia.

Intimate Partner Violence During Pregnancy⁷²

Global information fact sheet on the prevalence and consequences of intimate partner violence during pregnancy.

Women, Drug Policies, and Incarceration⁷³

A guide that urges policymakers in Latin America to take into consideration the multiple factors women charged with drug-related crimes have, for example, pregnancy and caring for dependents.

National Advocates for Pregnant Women⁷⁴

advocatesforpregnantwomen.org

A United States-based nonprofit offering legal advocacy and public education on the rights of pregnant women with a particular focus on women impacted by punitive “war on drugs” policies.

Endnotes

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Open Society Foundations

Active in more than 100 countries, the Open Society Foundations work to build vibrant and tolerant democracies whose governments are accountable to their citizens. Working with local communities, the Open Society Foundations support justice and human rights, freedom of expression, and access to public health and education.

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COVER:

A pregnant woman at home in Wisconsin. Citing a fetal protection law whose constitutionality is currently being challenged in federal courts, a judge ordered this woman a 78-day stay at a drug treatment center.

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PAGE 2:

A formerly homeless family in an independent housing unit supported by Programa Atitude, in Recife, Brazil.

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PAGE 4:

A mother, who is a client of a methadone clinic, dresses her child at home in Mombasa, Kenya.

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PAGE 7:

A family, who attend recovery support meetings together, pose for a photo in Los Angeles, California.

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PAGE 9:

A clinic director helps a new mother with enrollment paperwork at a drug treatment facility for pregnant and post-partum women in Rochester, New Hampshire.

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A mother receives methadone at a clinic in Kiev, Ukraine.

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A mother and her toddler daughter visit her newborn daughter at a hospital in Richmond, Kentucky.

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PAGE 19:

A pregnant woman at a residential treatment facility in Los Angeles, California.

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