From Just Say No to Just Say Know (and Do)

WISCONSIN ASSOCIATION
for **Perinatal Care**

This document was developed to describe a framework for comprehensive care of women with opioid use disorder. It is intended for stakeholders committed to improving the care for women with opioid use disorder.

DEFINITION OF OPIOID USE DISORDER

The *Diagnostic and Statistical Manual of Mental Disorders,* Fifth Edition (DSM-5) defines an opioid use disorder as, "A problematic pattern of opioid use leading to clinically significant impairment or distress, as manifested by at least two of the following, occurring within a 12-month period."

1. Opioids are often taken in larger amounts or over a longer period than was intended.
2. There is a persistent desire or unsuccessful efforts to cut down or control opioid use.
3. A great deal of time is spent in activities necessary to obtain the opioid, use the opioid or recover from its effects.
4. Craving, or strong desire or urge to use opioids.
5. Recurrent opioid use resulting in a failure to fulfill major role obligations at work, school, or home.
6. Continued opioid use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of opioids.
7. Important social, occupational or recreational activities are given up or reduced because of opioid use.
8. Recurrent opioid use in situations in which it is physically hazardous.
9. Continued opioid use despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance.
10. Tolerance, as defined by either of the following:
    a. A need for markedly increased amounts of opioids to achieve intoxication or desired effect.
    b. A markedly diminished effect with continued use of the same amount of an opioid.
11. Withdrawal, as manifested by either of the following:
    a. The characteristic opioid withdrawal syndrome.
    b. Opioids (or a closely related substance) are taken to relieve or avoid withdrawal symptoms.

CAUSES OF SUBSTANCE USE DISORDERS

As straightforward as the DSM-5 definition is, it is more difficult to identify a specific cause. A full description of the etiological pathways to substance use disorders is beyond the scope of this report. In general terms, substance use is influenced by genetic and environmental factors and their interactions with each other.

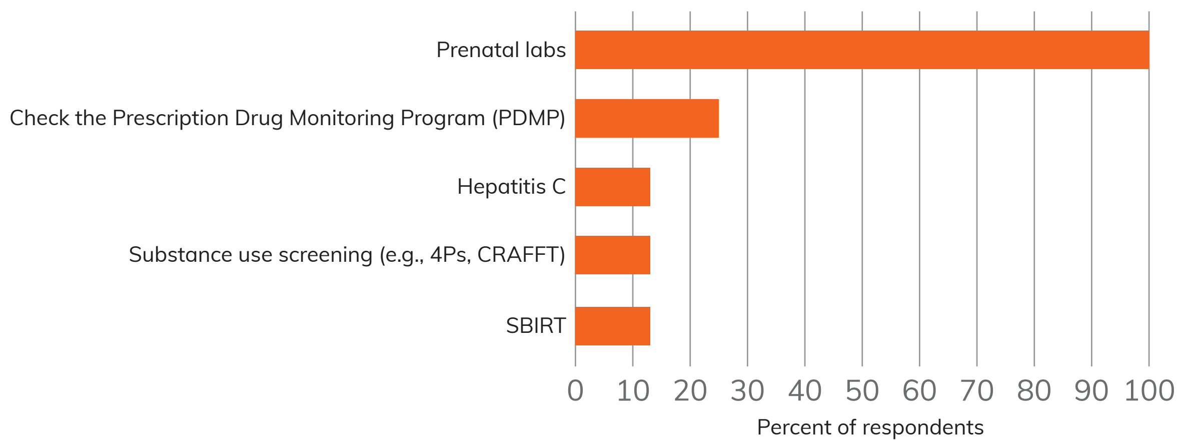
IN WISCONSIN

PROVIDERS' PERCEPTIONS

In May 2017, WAPC designed and distributed access to a survey to evaluate obstetric provider practice for women with substance use disorders. Access to the survey was sent to the Wisconsin Section of the American College of Obstetricians and Gynecologists (ACOG) and the Wisconsin chapter of the American College of Nurse-Midwives (ACNM). Ten providers responded, eight of whom indicated they provided care to women age 15–44 years with substance use disorders during pregnancy or the postpartum period.

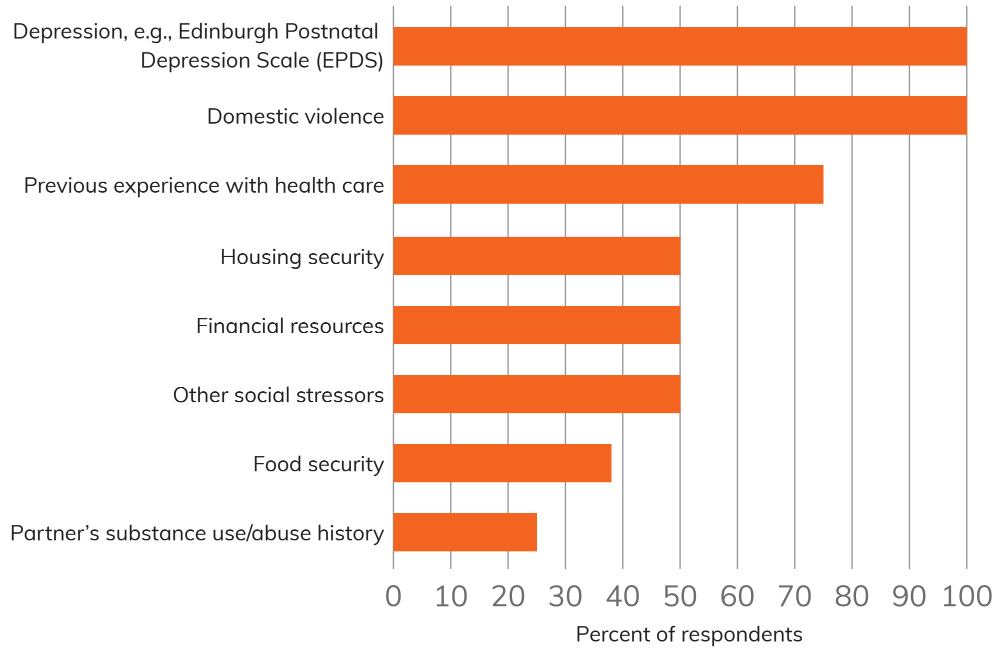
All providers responded that they or staff members routinely asked about past medical, reproductive, medication, infectious diseases, family, substance use/abuse, alcohol use/abuse, and tobacco use history. Six of eight respondents asked about nutrition. All providers also indicated they check routine prenatal labs. Fewer respondents indicated they routinely check hepatitis C or the Prescription Drug Monitoring Program (PDMP) and routinely use validated substance use screening tools or SBIRT (Screening, Brief Intervention, and Referral to Treatment). See the following charts.

Providers' Responses: Care Provided



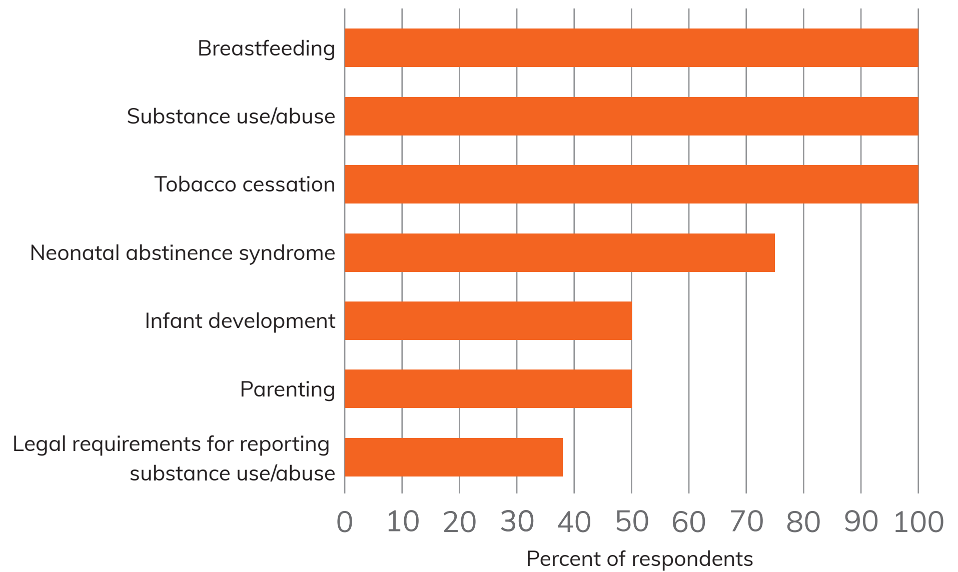
Providers' Responses: Screening

All providers indicated they screen for depression and interpersonal violence. Fewer ask about other psychosocial issues.



Providers' Responses: Information

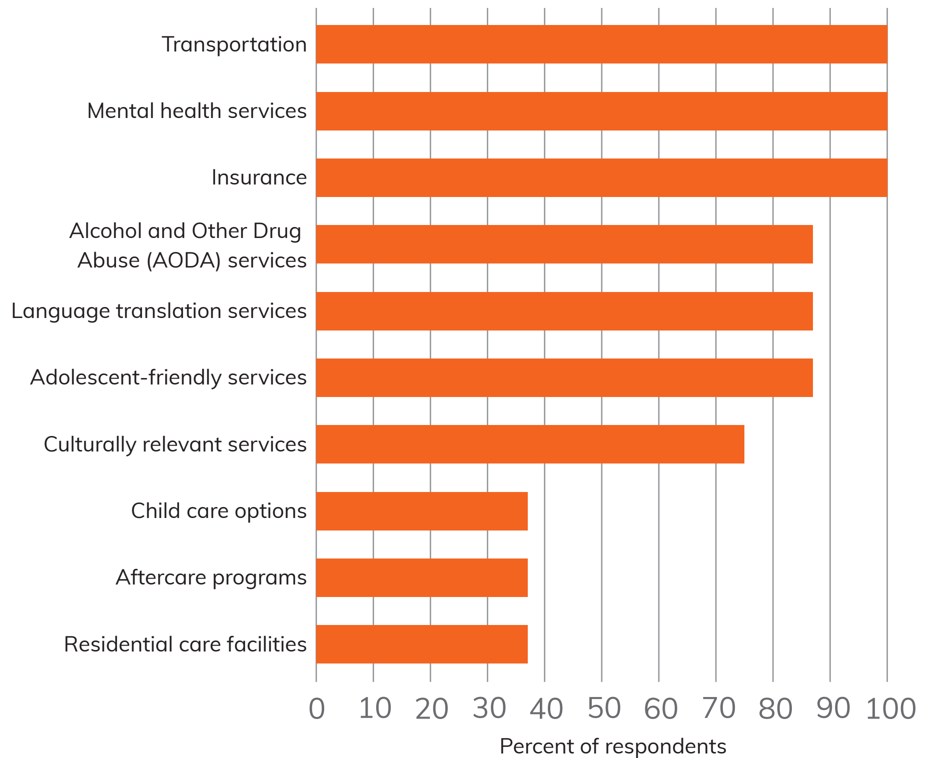
There was also variability in providers' or their staff members' ability to provide information during pregnancy.



"They don't give out information about resources at the beginning of pregnancy. It would help me to be prepared if I received this information early in my pregnancy."

Providers' Responses: Resource/Referral Information

Information availability on resources and referrals was mixed.



There are two significant limitations to the interpretation of this survey. First, the number and demographics of respondents does not permit generalizations across all providers. Second, the survey did not evaluate if women receiving care from the providers believed they received the care and information reported. At the same time, the providers who responded may represent a group of providers who are more aware of the implications of substance abuse.

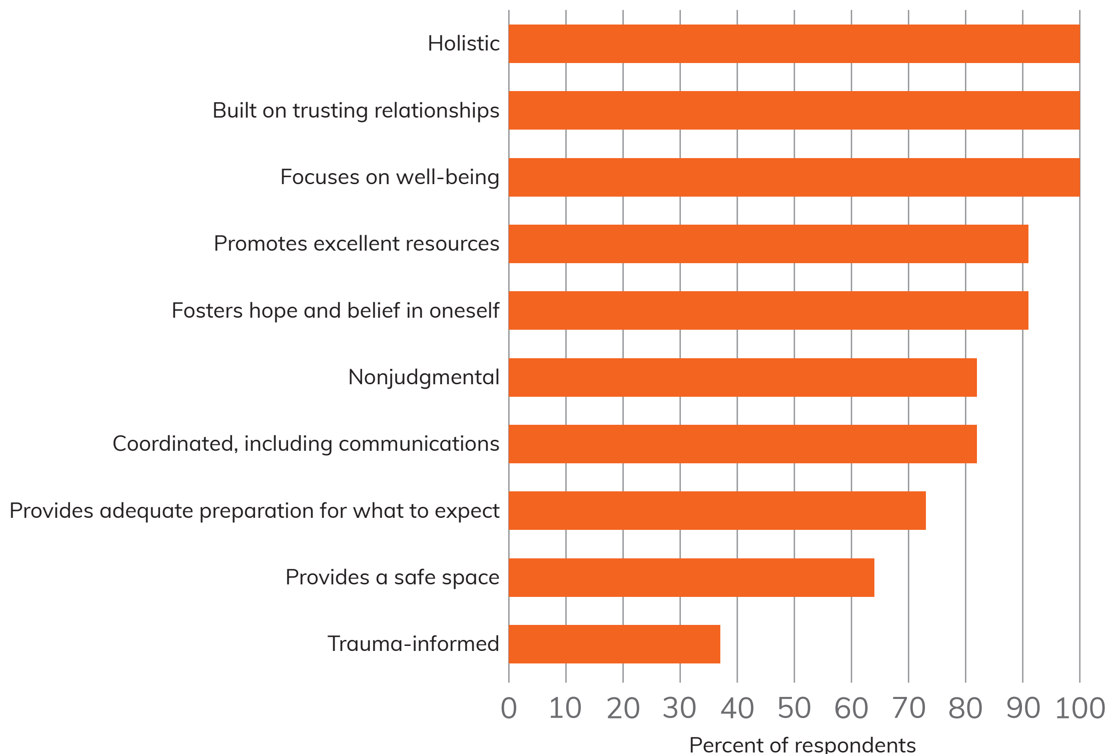
WOMEN'S PERCEPTIONS

How does care provided compare to the needs of women? Eleven women with histories of concurrent pregnancy and opioid use disorder were interviewed to understand their perceptions of the care they received. All interviews were conducted by the same interviewer using a standard set of questions. The interviewer also facilitated four focus groups of women who experienced pregnancy and opioid use disorder.

There was agreement between the individually interviewed women regarding the necessary components defining "quality" care.

> ***"What I value most is just somebody I can trust and feel confident in."***

Interviewed Women's Perceptions: Characteristics of "Quality" Care



"My OB (obstetric) provider contacted my MAT (medication-assisted treatment) program to verify the dose of my medication when I was in the hospital for labor and delivery."

Women also stressed the importance of support, through AODA programs, peers, and navigators.

Focus group participants recognized the value of holistic care along both medical and non-medical dimensions. They highlighted the importance of addressing mental health and chronic conditions as part of care. In addition, they noted the need for locally-available care.

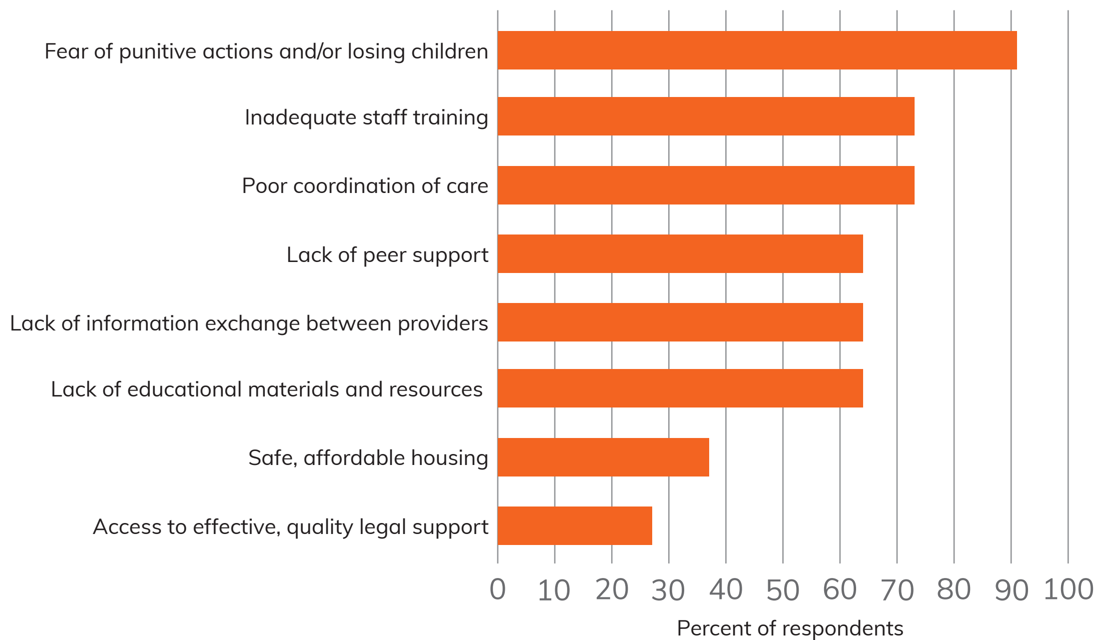
Non-medical care needs included factors that defined the context in which women lived—food security, safe and affordable housing, child care, and social support. Underlying these themes was a recognition of the need for self-empowerment, supported by legal and social advocates.

Women readily recognized the necessity of coordinated care and communication between providers and between providers and themselves. This would be facilitated by having appropriate signed releases of information for all care providers. Coordinated care and communication would ensure that providers not only shared accurate information about care, but also worked together on behalf of the woman and her fetus. The women also expressed the need for comprehensive care plans throughout the perinatal period addressing issues including pain management, support, and relapse prevention.

Focus group participants identified their educational needs as well as the needs of providers and the public. Some of the women did not believe they had adequate information on the effects of opioids on the care of the baby, including breastfeeding and neonatal withdrawal. Finally, they indicated a need for appropriate medication adjustment immediately after delivery and ongoing support for relapse prevention.

Care providers identified needs for education and training in client- and family-centered care, along with therapeutic communication skills. They also indicated that standardizing care protocols and using a team-based approach would support better care. Finally, they verbalized their fears and experiences related to misunderstanding and inconsistencies in interpretation of laws related to drug screening of pregnant women and newborn infants and reporting of substance use in pregnancy.

Individually interviewed women and women in the focus groups described barriers or gaps preventing them from receiving the care they need.



These gaps and barriers are compounded by lack of treatment providers in relation to overall numbers and distribution statewide and specifically for pregnant and postpartum women.

COMPREHENSIVE CARE

In routine care, most obstetric care providers obtain a complete history from their patients. Typically, the history includes past medical issues, surgical procedures, medications, alcohol use/abuse, tobacco use, and substance abuse. Providers may also ask about the health of family members, specifically parents and siblings. Some providers may ask about feelings of safety and feelings of depression.

In routine care, providers will likely order specific laboratory tests to evaluate for sexually transmitted infectious diseases, anemia and glucose instability. They may order imaging studies to confirm dates or assess fetal anatomy.

For many pregnancies, this care may be sufficient. For women affected by opioids, it does not address their needs. Given the complex nature of substance use disorders and how care is perceived and interpreted by women with opioid use disorder, it is essential to provide appropriate comprehensive, holistic, and compassionate care that centers the individual woman and incorporates an understanding of her life course.

Communication. Strong patient/provider relationships are built on trust. Knowing the woman's story is the starting point for a trusting relationship and developing a plan of care that will meet her needs. Women need appropriate information about their options and should be supported in their decisions. The environment should be safe and encourage open, honest, and nonjudgmental communication. Knowing how to form and forming therapeutic relationships with women are critical skills for providers.

"I was never judged. I was listened to. I was given options for treatment and recovery. My providers were open, honest, compassionate, caring, understanding and helpful."

Stigma. Stigma affects help-seeking, a process defined by a combination of intrapersonal and interpersonal factors. Institutional stigma refers to organizational policies and culture based on stigmatizing attitudes and beliefs. This type of stigma may not be readily recognizable by health care providers due to its incorporation into the culture of the organization. Health care providers can gain valuable insight into its existence by actively engaging those who may be affected. Social stigma is stigma held by a group of individuals toward another individual or group of individuals based on the negative value attributed to distinguishing characteristics held by the individual or group of individuals. Challenging one's negative beliefs and attitudes after introspective evaluation can be the first step providers take to address tacit acceptance of social stigma. Self-stigma is the acceptance by an individual of negative stereotypes. Self-stigma is associated with low self-esteem and self-efficacy, two factors associated with an individual's desire and ability to access and participate in health care.

Framework. A framework for comprehensive, holistic and compassionate care can be developed along biomedical and psychosocial dimensions. The following tables describe necessary components of comprehensive, holistic and compassionate care for pregnant women with substance use disorders with attention to needs along biomedical and psychosocial dimensions.

> ***"I feel I didn't receive enough information about the safety of taking my medications and breastfeeding."***

Biomedical

History	Discussion
Past medical	An accurate past medical history is essential for ongoing medical care. It can often give the provider the first insight into the patient's current health.
Reproductive history	In addition to past pregnancies and outcomes, the reproductive history should also include contraception use. Women with opioid use disorders have an unmet need for contraception. Contraception, as part of comprehensive care, could decrease the number of unplanned pregnancies and the number of infants with neonatal abstinence syndrome. Further, this discussion provides an opportunity to discuss reproductive life planning. The reproductive life plan identifies the needs of each individual and takes into consideration future intent, timing and number of pregnancies. The WAPC position statement, *Pre- and Interconception Care and Reproductive Life Planning*, includes additional relevant information.
Medication history	Medication history provides additional information of past conditions.
Infectious diseases history	History of infectious diseases provides information of potential ongoing medical issues or concerns.
Immunizations	Some women with opioid use disorder may have co-occurring chronic diseases. It is necessary to ensure adequate and appropriate immunizations, including seasonal influenza vaccines, are up to date.
Nutrition	Good nutrition is fundamental to good health.

Substance use/abuse history and screening	ACOG recommends screening for substance use as part of comprehensive obstetric care. Further, ACOG recommends it should be done at the first prenatal visit in partnership with the pregnant woman. Routine screening should be performed using validated screening tools such as 4Ps, NIDA Quick Screen, and CRAFFT (for women 26 years or younger). In addition to being HIPAA-compliant, the consent to release information for substance abuse treatment records must also comply with federal law 42 CFR Part 2 governing the use and disclosure of alcohol and drug abuse treatment records. WAPC provides a disclosure template in the Perinatal Substance Use and Abuse section of its website.
Alcohol history and screening	Universal screening for alcohol use should utilize empirically validated strategies to reduce identification bias.
Tobacco history and screening	Universal screening for tobacco use should utilize empirically validated strategies to reduce identification bias.
Family history	Family history should also include information on mental health and substance use disorders.
Laboratory	
Routine laboratory testing	Routine laboratory testing should follow current recommendations. See WAPC's *Laboratory Testing During Pregnancy*, 5th Edition. Since substance abuse is a risk factor for sexually transmitted infections (STIs), women should be retested at 28–30 weeks for syphilis and during the third trimester for chlamydia and gonorrhea. Women with a history of injection drug use should be retested during the third trimester for HIV and at delivery for hepatitis B. Other risk factors may require different screening schedules.
Hepatitis C	Women with significant risk factors, including history of injected or intranasally administered illegal drugs, should be offered antibody screening to identify risk of mother-to-child transmission of hepatitis C. For more information, see WAPC's *Laboratory Testing During Pregnancy*, 5th Edition.
Other	
Prescription Drug Monitoring Program (PDMP)	PDMP includes information on all medications dispensed by pharmacists to individual patients. It does not include methadone dispensed from the state medication-assisted treatment programs. Physicians can delegate someone to check the PDMP.
Screening, Brief Intervention, and Referral to Treatment (SBIRT)	According to ACOG, early universal screening, brief intervention (such as engaging the patient in a short conversation, providing feedback and advice), and referral for treatment of pregnant women with opioid use and opioid use disorder improve maternal and infant outcomes.
Follow-up visits	Women should see their obstetric care providers monthly until 28 weeks; every 2 weeks between 28 and 36 weeks; and weekly between 36 weeks and delivery.
Maternal-fetal medicine referral	If indicated
Antepartum fetal testing and surveillance	If indicated

Psychosocial components of care are framed by four functions of social support and address both screening and support needs. The four support functions are emotional, instrumental, informational, and companionship. Taken together, these functions can support self-efficacy and empowerment skill-building for women.

"I think giving women with opioid use disorder a chance to show what they are about, instead of judging them as bad mothers, is best."

Psychosocial	
Emotional Support (culturally appropriate)	
Support groups and peer support	Groups and peers with common histories can provide support based on common understanding and acceptance.
Spiritual support	Spiritual support can provide a strong framework for some women.
Mental health	Substance use disorders frequently co-occur with depression and anxiety. Women are at high risk for the development of postpartum depression, especially if infants are being treated for neonatal abstinence syndrome. Women should be assessed and referred as needed. Consider using a validated screening tool like the Edinburgh Postnatal Depression Scale (EPDS).
Interpersonal violence	Women with substance use disorders are at risk for interpersonal or intimate partner violence. An example of a screening tool is the Abuse Assessment Screen (AAS).
Addiction	Providers can consider using a standardized evaluation tool like the Addiction Severity Index.
Previous experience with health care	Women with a history of poor past experiences with the health care system may have ongoing difficulties with the system. Common negative experiences with health care include: stigma, discrimination, perception of being judged, fear of treatment termination due to pregnancy, and fear of removal of the infant or other children from the home due to reporting by health care providers.
Partner's substance use/abuse history	Partners may share a common substance use/abuse history. Ongoing use by the partner may jeopardize a woman's treatment and recovery.
Adverse Childhood Experiences (ACEs)	ACEs underlie substance use/abuse and other mental health issues for many women. Unless appropriate screening is performed, these issues may go unresolved, and it may be difficult to recover and maintain sobriety.
Other potential emotional stressors	Families may experience other emotional stressors that they view as part of their normative experiences. It is important that providers consider other emotional stressors and investigate the role family members and others can play in alleviating the stress.

Instrumental Support (culturally appropriate)	
Advocate/navigator	The health care system can be challenging to navigate. An advocate to support a woman at visits with providers, make appointments, find resources, etc., can improve the care experience.
Child care	Need for child care can prevent women from accessing resources.
Transportation	Need for transportation can prevent women from accessing resources.
Mental health services	Other mental health problems often co-occur with substance use disorders.
Alcohol and Other Drug Abuse (AODA) services	Well-structured AODA services can increase the likelihood of success with treatment.
Insurance	Health insurance can increase access to effective treatment.
Aftercare programs	Aftercare programs are designed to provide ongoing support for women with opioid use disorders.
Residential care facilities	Residential care may provide an environment that supports recovery. Some facilities have the capacity to accommodate significant others and children and provide support to them.
Housing security	Safe and affordable housing can be the foundation for women accessing resources.
Food security	Lack of food security can prevent women from accessing resources. WIC may be an option for some women and families.
Financial resources	Poor financial resources can directly affect a woman's ability to access treatment services and meet other health and non-health needs.
Informational Support (culturally appropriate)	
Communication with providers	Obstetric and pediatric providers can be sources of evidence-based information for women with substance use disorders.
Navigating the system	Regardless of past experiences with health care, women may benefit from information and resources to facilitate navigating the system. Specific information/resources on managing crises is essential, including hotlines, 24/7 support services, etc.
Educational counseling	Some women may need help completing requirements for graduation or other educational needs.
Employment counseling	Some women may need help with drafting a résumé and knowing how to interview for a job.
Parenting	Women with opioid use disorders may not be able to rely on their own experiences of being parented and may benefit from support for parenting.
Substance use/abuse	Women should receive accurate information on substance use as a medical problem and available resources.

Tobacco	Women should receive information on tobacco cessation resources.
Legal requirements	Laws and how they are interpreted can vary greatly. Women need to know and understand their rights under the law to support their ability to self-advocate.
Neonatal abstinence syndrome	Women should be assured that neonatal abstinence syndrome/neonatal opioid withdrawal syndrome is treatable. If possible, women should have the opportunity to meet with a neonatal care provider prior to delivery. Rooming-in can be a useful strategy for treating neonatal abstinence syndrome and may promote more effective parenting.
Infant development	Infant development is dependent on a range of exposures prenatally and postnatally. Infants of women with opioid use disorders may also be exposed to other factors that can adversely affect development.
Breastfeeding	Provider-directed use of opioids is not an absolute contraindication to breastfeeding. Women should have access to breastfeeding support from lactation consultants.
Companionship	
Fathers/partners/others in woman's support network	Supportive relationships can aid recovery. Providers should offer relationship support/counseling.

CARE FOR MOTHER AND INFANT AFTER DELIVERY

The following table identifies some of the ongoing needs of women and infants affected by opioids.

Women	
Obstetric follow up	Women should have ongoing obstetric follow-up to address issues related to pregnancy and delivery. In addition, follow-up should include reproductive life planning.
Primary care	It is important to develop a relationship with a care provider who is sensitive to and able to meet the woman's ongoing health care needs.
Opioid use disorder management	Ongoing care should include evaluation and adjustment of any medication doses as needed.
Mental health support	Mental health support can be combined with management of substance use disorder if the provider is qualified to manage both.
Peer support	Peer support may facilitate the transition into a range of community-based services.
Other community services	Includes services that address ongoing needs, including financial, parenting, etc.
Partner's substance use/abuse history	Partners may share a common substance use/abuse history. Ongoing use by the partner may jeopardize a woman's treatment and recovery.
Infants	
Well-child care	Infants need routine health services.
Developmental follow up	Infants exposed to substances or other physiological stresses in utero may be at higher risk for development delays.

There are challenges to providing comprehensive care as outlined previously. In the most general and simple terms, challenges may be related to availability, accessibility, acceptability, and affordability. In reality, challenges are more likely to be multifactorial and may affect care at patient and provider levels.

RECOMMENDATIONS

1. Providers should address the barrier to care imposed by institutional, social, and self-stigma.
2. Care should be person-centered and incorporate the strengths and needs of the woman.
3. Care should be offered in a compassionate, safe, and supportive environment.
4. Care should be comprehensive and holistic.
5. Care should be seamless across the perinatal continuum.
6. Care for the woman should also include the needs of her infant.
7. If unable to provide services directly, providers should identify and engage resources in the community.
8. Women and providers should work collaboratively to identify needs and leverage additional resources when needed.

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