A Blueprint for Action
Improving Care for Women and Infants Affected by Opioids

Executive Summary
For many women and infants affected by opioids, there are significant gaps between the care they receive and the ideal. The gaps can compromise care throughout the perinatal continuum—during the preconception period and pregnancy; during labor, delivery, and birth; and after delivery. Stakeholders recognize the necessity of addressing the problems, but are faced with barriers that impede their abilities to improve care. As a result, there are significant gaps in care and less than optimal outcomes for women and infants.

Nationally, there have been increases in the numbers of women and infants affected by opioids over the past 15 years. Wisconsin has probably experienced the same increases, but data are limited. At the same time, a range of barriers has prevented stakeholders from addressing the issues adequately.

This blueprint is a document from which stakeholders can collaborate and coordinate efforts to improve care for women and infants affected by opioids. It identifies six areas for change that are intended to focus on major areas that can improve care of women and infants and lead to better outcomes. The strategies it recommends require commitment of a range of stakeholders—women, families, providers, policymakers, law enforcement, and the media. It is our firm belief that implementing the strategies will address the deficiencies and weaknesses of the current system of care and lead to a system that is closer to the ideal.

The six areas of change are
1. Community engagement to improve care for women and infants affected by opioids
2. Identification and implementation of best practices for care of women and their infants
3. Education and educational resources for women and health care providers
4. Diagnostic and treatment resources for women and their partners
5. Public policies that support women and families
6. Data to support continuous improvement of care for women, infants, and families

The objectives and strategies associated with these areas give multiple stakeholders the opportunity to examine their capacities to contribute to the solution and improve the care for women and infants affected by opioids.

In an Ideal World
In an ideal world, a woman on opioids would experience her reproductive life in a caring and supportive environment. She would feel comfortable talking to her provider about her substance use prior to becoming pregnant and her provider would discuss her substance use in a non-judgmental manner, either helping her quit or referring her to an equally caring and concerned provider with expertise in substance use disorders. If she were unable to quit, she and her providers would weigh the pros and cons of her current substance use and adjust her medication and dosing regimen to prepare for an optimal pregnancy outcome. In addition, they would contact her pediatric care provider and he/she would meet with the woman to discuss her needs and the needs of her infant after delivery. Community health service providers would meet with her to assure she received help for comorbid conditions; her partner received help, if needed; her other children received help, if needed; her work place provided a supportive environment; the criminal justice system focused on rehabilitation; and that she had all the resources she needed to support her during and after pregnancy. Throughout the continuum, a woman and her family would receive support focused on assuring the best health outcomes.
In Reality—

In reality, the continuum of perinatal care often does not lead to the best outcomes or meet the needs of women and infants affected by opioids.

Preconception and during pregnancy

Substance use disorders and women affected by them are stigmatized. Health care providers may not understand and be sensitive to substance use disorders and may lack knowledge of management strategies and treatment resources. Health care providers may not follow recommendations from the American College of Obstetricians and Gynecologists to screen women for substance use disorders. Screening and reporting can be used to quantify the magnitude of the problem for women and assure appropriate treatment. Care providers may not recognize or screen for comorbid conditions that can adversely affect women's care for substance use disorders. Additionally, the environment in which a woman lives and the people with whom she lives may support and enable substance use disorders. These problems are further complicated by inadequate availability of treatment resources.

Labor, delivery, and birth

During labor and delivery, women may face additional stigma as “drug users,” which can negatively affect their ability to receive appropriate pain medication. Neonatal care may be fragmented or inappropriate. Infants may not be screened for neonatal abstinence syndrome if providers do not identify risk factors for withdrawal. Care providers may not be aware of appropriate neonatal management strategies.

After delivery

For the woman, there may be questions about her ongoing care—management of her substance use disorder and developing or maintaining her social support—and ability as a parent. For the infant, there may be questions related to safety, breakthrough withdrawal, or long-term effects on neurodevelopment.

Throughout the continuum

Society may adopt standards it believes protect its best interest. Resultant legislation may lead to punitive approaches with unintended consequences. Women may be detained or incarcerated by the criminal justice system and lose access to health care or employment.

The remainder of this document provides a blueprint for action to improve care of women and infants affected by opioids and move Wisconsin closer to the ideal.

Background

Over the past 15 years, there have been significant increases in the number of women affected by opioids during pregnancy and the number of infants experiencing neonatal abstinence syndrome. From 1998 to 2009, opioid use was documented in 25 per 10,000 pregnancy-related hospital discharges. After a statistically significant downward trend between 1998 and 2001, there was a statistically significant trend to 40.3 per 10,000 between 2002 and 2009. Women between 20 and 29 years experienced the most pronounced increases (Salihu, Mogos, Salinas-Miranda, Salemi, & Whiteman, 2014). Similarly, the prevalence of neonatal abstinence syndrome increased from 1.2/1000 live births in 2000 to 3.39/1000 live births in 2009 (Patrick, Schumacher, Benney, Krans, McAllister, & Davis, 2012).

One possible reason for the increases in women affected by opioids and neonates experiencing withdrawal is greater awareness and identification of the problems by health care providers. Although this may explain some of the increase, another significant contributing factor to the problem is an increase in prescribed opioids. In 2001, the Joint Commission made pain the “fifth vital sign” and health care providers changed practice behaviors to address patient pain more aggressively. Since that time, the number of prescriptions filled for opioids has increased significantly (Manchikanti, Helms, Fellows, Janata, Pampati, Grider, & Boswell, 2012).

In contrast to the increase in availability of opioids, there are barriers to accessing care for substance use disorders. Jackson and Shannon (2012) surveyed 114 urban and
rural pregnant women entering inpatient detoxification to identify treatment barriers. They reported no significant differences between urban and rural women on issues related to affordability, availability, accessibility, and acceptability. Overall, 81.2% of rural women and 89.7% of urban women experienced barriers to substance abuse treatment, including transportation difficulties, inadequate childcare, waiting periods, and insurance or financial issues.

WISCONSIN ASSOCIATION for Perinatal Care

Wisconsin

The situation in Wisconsin appears to reflect the trends in other states. In 2013, there were 66,566 live births in Wisconsin (Wisconsin Department of Health Services, Division of Public Health, Office of Health Informatics, 2014). The number of women who may have had a substance use disorder is unknown, but estimates are likely lower than the actual number (Schauberger, Newbury, Colburn, & Al Hamadani, 2014). Similarly, the number of infants treated for neonatal abstinence syndrome and how they are distributed among the state’s approximately 100 birth hospitals is also unknown. Information related to maternal opioid use and neonatal abstinence syndrome is available from a variety of sources, but there are inherent deficiencies in the data. Billing data based on diagnostic and treatment codes are available, but may not capture all women and infants because of inaccurate assessment and interpretation of clinical information. Research data can provide information, but require knowledge of the context in which they are obtained. In addition, collection of data associated with illegal drug use may increase the threat of legal consequences, inhibiting women from disclosing accurate information (Bornstein, 2003). Surveillance data, collected anonymously to determine the magnitude of the problem, are missing.

There are 15 opioid treatment programs in Wisconsin. Over 180 buprenorphine providers and 60 buprenorphine treatment programs also serve patients throughout the state (Substance Abuse and Mental Health Services Administration, US Department of Health and Human Services). Despite the number of treatment options, women face barriers to care.

In 2014, the Wisconsin legislature passed a series of bills collectively known as the H.O.P.E. (Heroin, Opioid, Prevention, and Education) Agenda. The legislation, comprised of seven bills, addressed four issues related to the opioid epidemic and its effects on women and infants.

- Act 194 provided limited immunity from certain criminal prosecutions for a person who seeks assistance from the police or medical professionals for another individual who has overdosed on controlled substances.
- Act 195 created regional pilot programs to address opioid addiction in underserved areas. The treatment programs will assess individuals to determine treatment needs, provide counseling, and medical or abstinence-based treatment.
- Act 197 expanded Treatment and Alternatives and Diversion programs by increasing funding by $1.5 million annually.
- Act 200 provided all levels of EMTs, first responders, police, and firefighters the ability to be trained to administer naloxone, a drug used to counter the effects of opioid overdose.

Proponents view the H.O.P.E. Agenda as the foundation for how Wisconsin addresses the problem of opioid addiction now and in the future by focusing on short- and long-term needs and resources.

WAPC

Through continuous community engagement, the Wisconsin Association for Perinatal Care (WAPC) has been active in improving care for women and infants affected by substance use disorders for nearly three decades. In 1989, Wisconsin Act 122 created a task force to combat controlled substance use by pregnant women with young children. It also funded a major effort to address the problems of perinatal addiction and the problems related to needed services for pregnant women or women with young children. Through a competitive process, the Wisconsin Department of Health Services awarded WAPC a grant to create a system and provide professional education. Through engagement with over 60 local, regional, and statewide organizations and individuals, the effort resulted in publication of Challenges in Perinatal Substance Abuse: Educational Strategies for Care Providers and Communities (Collaborative Workgroup on Perinatal Substance Abuse Education, 1989) and a series of educational offerings in seven locations.

In 2004, recognizing the increasing issue of prescribed maternal opioids, WAPC’s Infant and Family Committee began an initiative to address the issue of neonatal opioid withdrawal. The Committee’s work resulted in the 2011 WAPC Regional Forum Series, “The Effects of Opioid Dependence during Pregnancy—Addressing both Maternal and Neonatal
Issues," a statewide educational program offered in seven geographical locations. In addition, the committee developed the Newborn Withdrawal Project Educational Toolkit (Wisconsin Association for Perinatal Care).

In 2014, WAPC reaffirmed its commitment to improving care for women and infants affected by opioids with a programmatic agenda directed at increasing collaboration and identifying strategies for improving care. With funding from the Title V MCH Block Grant and the Perinatal Foundation, WAPC hosted a meeting of stakeholders charged with setting priorities for actions to improve care of women and infants affected by opioids. Nearly 200 stakeholders gathered in Madison on July 25, 2014, to discuss issues related to care. Participants interacted with three content panels and focused on three divisions of the perinatal continuum—before and during pregnancy, at birth, and postpartum through the infant’s first year of life. The final hour of the program was dedicated to an expert panel whose members reflected on what they heard, what they knew, and what they experienced to highlight priority areas. Meeting participants completed a Strengths, Weaknesses, Opportunities, and Barriers (SWOB) assessment in which they considered their work environments and reflected on the resources available and resources needed to improve care of women and infants affected by opioids. The Regional Forum Planning Group used the information from the panels and the SWOB analyses to develop the curriculum for the 2014 Regional Forum Series.

The Blueprint “Specs”

This blueprint details specific strategies for improving care of women and infants affected by opioids garnered through continuous community engagement over the past 25 years. The blueprint assumes a broad definition of care to include not only biomedical health care, but also psychosocial care. The strategies require commitment of a range of stakeholders—women, families, providers, policymakers, law enforcement, and the media. It is our firm belief that implementing the strategies will address the deficiencies and weaknesses of the current system of care and lead to a system that is closer to the ideal.

**Improving care for women and infants affected by opioids centers on six areas for change:**

1. Community engagement to improve care for women and infants affected by opioids
2. Identification and implementation of best practices for care of women and their infants
3. Education and educational resources for women and health care providers
4. Diagnostic and treatment resources for women and their partners
5. Public policies that support women and families
6. Data to support continuous improvement of care for women, infants, and families

The section that follows outlines the system goals and strategies.
### Area for change:

1. **Community engagement to improve care of women and infants affected by opioids**

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<thead>
<tr>
<th>System Goals and Strategies</th>
<th>Perinatal Period*</th>
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<tbody>
<tr>
<td><strong>Raise awareness of substance use and substance use disorders.</strong></td>
<td>PC/P LDB PP TPC</td>
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<tr>
<td>Give a face to opioid use by collecting and promoting stories of real women, moving beyond the stereotypes of substance use disorders.</td>
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**For example,**
- Engage women treated with methadone prior to delivery to develop collaborative relationships between the women and health care providers (E.M. Goetz, personal communication, July 25, 2014).
- Share stories of women with substance use disorders, chronic pain, and long-term pain management (Wisconsin Association for Perinatal Care Store, Salena's Story).

<table>
<thead>
<tr>
<th><strong>Create community conversations by engaging stakeholders.</strong></th>
<th>PC/P LDB PP TPC</th>
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<tr>
<td>Support community and regional coalitions of diverse stakeholders, including women and families affected by opioids in pregnancy, representatives of maternal and infant health care communities, community service agencies, substance use/abuse counselors and opioid treatment programs, legislative bodies, law enforcement, the judicial system, and the media, with a focus on improving care for women and infants affected by opioids.</td>
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**For example,**
- Organize meetings of hospital and community-based health care providers, social service providers, law enforcement, and others to begin a conversation about women and infants affected by opioids (E. Abler, personal communication, May 16, 2013).
- Safe Communities Madison-Dane County leads a collaborative effort to reduce access and use/misuse of prescription opioids (Safe Communities Madison-Dane County).
- Recruit coalition members from a broad group of community stakeholders to assure diversity (Chin & Abesamis-Mendoza, 2012; Firesheets, Francis, Barnum, & Rolf, 2012).

**PC/P=preconception and pregnancy; LDB=labor, delivery, and birth; PP=postpartum; TPC=throughout perinatal continuum**

2. **Identification and implementation of best practices for care of women and their infants**

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<tr>
<td><strong>Increase the number and quality of evidence-based prevention services.</strong></td>
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<tr>
<td>Work with stakeholders to promote education for teens.</td>
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<tr>
<td>Work with the stakeholders to promote non-pharmacological strategies for pain management and responsible prescribing of opioids.</td>
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**For example,**
- Engage adolescents in schools focusing on prevention and interventions, as needed (Benningfield, Riggs, & Stephan, 2015).
- Utilize community-based coalitions to implement comprehensive, research-based prevention strategies to reduce substance use prevalence among adolescents (Hale, LaPlante, Liebig, Piasecki, & Uerz, 2005).
- Engage third party payers to monitor opioid prescribing and follow-up with prescribers as needed (K. Schellhase, personal communication, October 30, 2014).
- Screen women of reproductive age (American College of Obstetricians and Gynecologists, 2012).
### System Goals and Strategies

#### Identify best practices and disseminate them to care providers.

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Convene group of experts to develop an evidence-based model of care for pregnant women on opioids.

Convene group of experts to develop an evidence-based model of care for neonates experiencing neonatal abstinence syndrome.

Develop coordination of care model with algorithm for shared care.

Develop resource list of experts for issues related to care of women and infants.

For example,
- Devote hospital resources for developmentally supportive environments for care of infants with NAS (Hodgson & Abrahams, 2012).
- Tailor messages for drug prevention to meet the needs of the intended audiences (Backer, 2000).
- Develop and disseminate protocols for management of NAS (Hall, Wexelblatt, Crowley, Grow, Jasin, Klebanoff, McClead, Meinzen-Derr, Mohan, Stein, & Walsh, 2014).

#### Promote implementation of best practices for care of women and infants to care providers.

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Work with maternal and infant care providers to develop strategies to overcome identified barriers to implementation.

Work with maternal and infant care providers to coordinate services.

Promote communication between all care providers and develop resources to eliminate barriers and facilitate care of women and infants.

For example,
- The Wisconsin Association for Perinatal Care hosted a Webinar on screening infants for neonatal abstinence syndrome (Wisconsin Association for Perinatal Care Courses, 2013).
- Use evidence-based screening tools (Wallman, Bohling Smith, & Moore, 2011).

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### 3. Education and educational resources for women and health care providers

#### System Goals and Strategies

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Educate maternal and infant care providers on substance use and substance use disorders.

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Develop and disseminate fact sheets on opioids and pregnancy.

Develop educational materials addressing addiction science for providers.

Work with educational programs (medical, nursing, social work, etc.) to assure appropriate education on addiction and substance use disorders.

Provide continuing education opportunities (Webinars and live conferences) on managing women and infants affected by opioids.

Provide training to assist women in recovery.

Develop guidelines and tools for reproductive health planning.

For example,
- Adopt policies for pain management (Federation of State Medical Boards, 2013).
- Model non-judgmental behaviors (Kelly & Westerhoff, 2010).
- Support women in opioid treatment programs (Registered Nurses’ Association of Ontario, 2009).
- Reduce stigma with focused education (Woods & Joseph, 2012).
### System Goals and Strategies

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<tbody>
<tr>
<td><strong>Educate consumers on the impact of opioid use during pregnancy.</strong></td>
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<tr>
<td>Develop and disseminate information on substance use and substance use disorders for women of reproductive age.</td>
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<tr>
<td>Work with opioid treatment centers and buprenorphine prescribers to assure appropriate education of consumers, including impact of opioid use during pregnancy and the importance of reproductive health planning.</td>
<td>X</td>
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<tr>
<td>Augment list(s) of resources available for treatment of substance use disorders.</td>
<td>X</td>
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**For example,**

**Educate other community partners.**

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<tr>
<td>Identify key thought leaders in business, education, and other sectors, and promote information on substance use disorders.</td>
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**For example,**
- Provide a context for opioid use in pregnancy (Patrick et al., 2012).

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### 4. Diagnostic and treatment resources for women and their partners

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<tr>
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<tr>
<td><strong>Increase availability, acceptability, accessibility, and affordability of screening, treatment, and education services.</strong></td>
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**Availability**

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<tr>
<td>Work with legislators, the Department of Health Services, the State Opioid Treatment Authority, and others to secure treatment services for those in underserved areas of the state.</td>
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<tr>
<td>Work with medical groups to promote training for physicians interested in prescribing buprenorphine.</td>
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<tr>
<td>Work with Medicaid and other insurers to increase incentives for health care providers to work with women with mental health or substance use disorders.</td>
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<tr>
<td>Identify and collaborate with other groups working to improve availability.</td>
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<tr>
<td>Work with the Department of Corrections to assure appropriate treatment for incarcerated women.</td>
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<tr>
<td>Increase awareness of available resources by identifying mental health providers with interest in substance use disorders.</td>
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**For example,**
- Assembly Bill 668: Expands Treatment Alternatives and Diversion (TAD) programs by increasing funding by $1.5 million annually (Nygren, 2014).
- Assembly Bill 701: Creates regional pilot programs to address opiate addiction in underserved areas. The treatment programs will assess individuals to determine treatment needs, provide counseling, and medical or abstinence-based treatment (Nygren, 2014).
System Goals and Strategies

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Increase availability, acceptability, accessibility, and affordability of screening, treatment, and education services.

**Acceptability**

- Incorporate screening questionnaires for all pregnant women for medication use and substance use disorders as a best practice.
  
  - For example,
    - Incorporate screening into routine care of women (American College of Obstetricians and Gynecologists, 2012).

- Incorporate consumer education on substance use disorders at maternal and infant care visits.
  
  - For example,

**Accessibility**

- Increase priority of pregnant women seeking help from buprenorphine prescribers.
  
  - For example,
    - Make NAS a reportable disease for surveillance only (Warren, 2013).
    - Treat substance abuse disorders as health issues (Volkow, 2014).

- Incorporate appropriate aftercare services into home visiting programs.
  
  - For example,
    - Treat substance abuse disorders as health issues (Volkow, 2014).

- Develop telepsychiatry services for perinatal substance use disorder treatment.
  
  - For example,
    - Treat substance abuse disorders as health issues (Volkow, 2014).

**Affordability**

- Work with Medicaid and other insurers to assure coverage for substance use disorder screening and treatment.
  
  - For example,
    - Treat substance abuse disorders as health issues (Volkow, 2014).

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5. Public policies that support women and families

System Goals and Strategies

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Support public policies that focus on rehabilitation.

- Identify model legislation and policies that promote evidence-based responses to behavior.
  
  - For example,
    - Make NAS a reportable disease for surveillance only (Warren, 2013).
    - Treat substance abuse disorders as health issues (Volkow, 2014).
## System Goals and Strategies

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<tr>
<td><strong>Engage legislators, law enforcement, and the judicial system.</strong></td>
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<td>Educate stakeholders on the needs of women with substance use disorders.</td>
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<td>Develop public policies that support responsible prescribing practices.</td>
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<td><strong>For example,</strong></td>
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<tr>
<td>• Certify or register pain clinics (National Alliance for Model State Drug Laws and the National Safety Council, 2014).</td>
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### Facilitate use of the Prescription Drug Monitoring Program (PDMP) in perinatal care.

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<tr>
<td>Increase use of the PDMP by maternal care providers.</td>
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<td>Enable use of PDMP by public health workers.</td>
<td>X</td>
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<td>Enable use of PDMP by advanced practices nurses with prescribing privileges.</td>
<td>X</td>
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<td><strong>For example,</strong></td>
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<tr>
<td>• Focus outreach efforts to medical professionals to increase use of the PDMP (Florida Office of the Attorney General, 2014).</td>
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### 6. Data to support continuous improvement of care for women, infants, and families

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<tbody>
<tr>
<td><strong>Collect data on women and infants affected by opioids to inform policy, monitor progress and trends, and evaluate interventions.</strong></td>
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<tr>
<td>Enhance PeriData.Net® to collect and report trend data related to substance use disorders.</td>
<td>X</td>
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<tr>
<td>Collect data from opioid treatment programs on numbers and characteristics of women of reproductive age and numbers and characteristics of pregnant women.</td>
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<tr>
<td>Coordinate with other agencies that work with pregnant women to share information on women on opioids</td>
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<tr>
<td>Create a public health surveillance system to collect data to define the problem of maternal opioid use in pregnancy</td>
<td>X</td>
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<tr>
<td>Collaborate with the Wisconsin Perinatal Quality Collaborative to collect information and make recommendations for improvements in care.</td>
<td>X</td>
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<tr>
<td><strong>For example,</strong></td>
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<td>• Track and report opioid prescribing (Liu, Logan, Paulozzi, Zhang, &amp; Jones, 2013).</td>
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<td>• Track and report maternal use of opioids during pregnancy.</td>
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<td>• Track and report neonatal outcomes (J. Ancona, personal communication, May 21, 2014).</td>
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*PC/P=preconception and pregnancy; LDB=labor, delivery, and birth; PP=postpartum; TPC=throughout perinatal continuum
Next steps

Maternal opioid use and neonatal abstinence syndrome are significant public health problems for which there are no easy solutions. The complexity of substance use disorders, in general, requires a comprehensive and multifaceted approach. Ideally, prevention of maternal substance use disorders is the primary goal. However, given the number of women already affected and the number of women who become addicted through exposure to prescribed opioids, preventive approaches should be integrated with strategies to address existing addiction. Similarly, preventing neonatal abstinence syndrome is the goal. Again, the challenge is that many women are already addicted to opioids. Thus, an additional essential focus is on care of the infants at risk for and those who have neonatal abstinence syndrome.

This Blueprint describes six areas for change and a number of objectives and strategies that could facilitate improvements in care for women and infants affected by opioids and fill the gap between the real and the ideal. These strategies are based on the following assumptions:

1) Change must encompass the continuum of care.
2) Women and infants have contact with many stakeholders during the perinatal period.
3) Providers have the tools and the desire to improve care.
4) Stakeholders will collaborate with each other to assure the best outcomes for women, infants, and families.
5) The people of Wisconsin want to do better to improve perinatal outcomes for all women, infants, and their families.

The biggest challenges facing stakeholders wanting to improve care of women and infants affected by opioids are recognizing how they can contribute to the solution and committing to making a difference.

References


