A Strategic Roadmap to Address America's Silent Health Crisis: Untreated and Unaddressed Perinatal Mental Health Disorders, Led By Postpartum Support International
Introduction

This report provides information on the Mind the Gap Initiative, led by Postpartum Support International in partnership with national organizations, including an overview of the Initiative, consensus-informed priorities, and specific actions from organizations to collectively advance and improve outcomes for Perinatal Mental Health. The Executive Summary provides the synopsis with the subsequent report providing further details and commentary.

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# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>04</td>
</tr>
<tr>
<td>WHAT IS THE GAP?</td>
<td>10</td>
</tr>
<tr>
<td>UNDERSTANDING THE IMPACT</td>
<td>11</td>
</tr>
<tr>
<td>Women</td>
<td>11</td>
</tr>
<tr>
<td>Women at Higher Risk</td>
<td>12</td>
</tr>
<tr>
<td>Maternal Mortality and Perinatal Mental Health</td>
<td>13</td>
</tr>
<tr>
<td>Fathers</td>
<td>14</td>
</tr>
<tr>
<td>Infants and Children</td>
<td>14</td>
</tr>
<tr>
<td>A High Cost in Health Outcomes</td>
<td>14</td>
</tr>
<tr>
<td>Adverse Workplace Impact</td>
<td>15</td>
</tr>
<tr>
<td>BEHIND THE GAP</td>
<td>16</td>
</tr>
<tr>
<td>An Action Deficit</td>
<td>16</td>
</tr>
<tr>
<td>A Treatment Deficit</td>
<td>16</td>
</tr>
<tr>
<td>A System Deficit</td>
<td>17</td>
</tr>
<tr>
<td>A Dollar Deficit</td>
<td>18</td>
</tr>
<tr>
<td>BRIDGING THE GAP</td>
<td>19</td>
</tr>
<tr>
<td>MIND THE GAP FRAMEWORK</td>
<td>20</td>
</tr>
<tr>
<td>FIVE SHARED PRIORITIES</td>
<td>21</td>
</tr>
<tr>
<td>GUIDING PRINCIPLES</td>
<td>23</td>
</tr>
<tr>
<td>ACTIONS</td>
<td>24</td>
</tr>
<tr>
<td>MIND THE GAP — CALL TO ACTION</td>
<td>35</td>
</tr>
<tr>
<td>MIND THE GAP ADVISORY WORK GROUP</td>
<td>37</td>
</tr>
<tr>
<td>ORGANIZATIONS</td>
<td>38</td>
</tr>
<tr>
<td>LEADERSHIP AND CONVENEERS</td>
<td>38</td>
</tr>
<tr>
<td>SUPPORTERS</td>
<td>39</td>
</tr>
<tr>
<td>SUPPORTER ACKNOWLEDGEMENTS</td>
<td>40</td>
</tr>
<tr>
<td>CONTRIBUTORS</td>
<td>42</td>
</tr>
<tr>
<td>WHY WE CHOSE MIND THE GAP</td>
<td>44</td>
</tr>
<tr>
<td>ABOUT PSI &amp; THE REILLY GROUP</td>
<td>46</td>
</tr>
<tr>
<td>PSI FACT SHEET</td>
<td>48</td>
</tr>
<tr>
<td>CITATIONS</td>
<td>50</td>
</tr>
</tbody>
</table>
Executive Summary

Mind the Gap: A Strategic Roadmap to Address America’s Silent Health Crisis: Untreated and Unaddressed Perinatal Mental Health Disorders, Led By Postpartum Support International
Executive Summary

Perinatal Mental Health refers to a woman's mental health during pregnancy as well as the first 12 months after delivery. A range of mental health disorders including depression and anxiety can affect mothers during this period.

Mind the Gap is a Collective Impact Initiative led by Postpartum Support International (PSI), in partnership with a broad-based stakeholder coalition comprised of leading experts from national professional and advocacy organizations. This unprecedented partnership unites multiple disciplines, fields, and specialties around a shared goal to: Ensure Perinatal Mental Health is a National Priority.

Perinatal Mental Health is an urgent public health issue in the United States. Baseline numbers indicate that at least 600,000 women will develop perinatal depression each year related to a live birth — and the total numbers are likely far higher when other mental health disorders are included. These disorders affect not only the health of mothers, but also have a demonstrated impact on the father’s mental health and on infant and child development, including the mental and physical health of babies and the entire family — as well as the workplace. And this impact is both acute and long-term.

Yet despite the impact and prevalence of Perinatal Mental Health disorders, there are significant disparities across the nation — in public awareness, health professional education and training, and research, and, on the patient side, coverage of and access to screening, diagnosis, treatment, support, and prevention services. This is the Gap.

To bridge that gap and address these challenges will require a national conversation and specific, targeted actions in the areas of policy, outreach, and healthcare delivery, along with establishing a national coordinating entity. The Mind the Gap Initiative has identified a unified strategic roadmap of priorities, based on research and consensus. Through collective action and partnership, this roadmap will be implemented.

After decades of discussion, the time has come to close the gap in the undertreatment of Perinatal Mental Health disorders. This is the intent of the Mind the Gap Collective Impact Initiative. By comprehensively addressing Perinatal Mental Health, PSI’s Mind the Gap Initiative seeks to improve the outcomes for not only mothers, but also for infants, fathers, families, and communities.
Executive Summary

Who We Are

Led by PSI, Mind the Gap is a Collective Impact Initiative comprised of women leaders with lived experience, and other leaders from professional and advocacy organizations representing pediatric health, public health, maternal mental health, mental health, women’s health, as well as academia, health systems, government agencies, major medical centers, and private sector supporters – all working toward improving Perinatal Mental Health. (See Advisory Work Group List)

Assessment

Using a Landscape Analysis conducted by The Reilly Group, Mind the Gap first identified significant gaps, disparities, and challenges related to Perinatal Mental Health disorders. Second, the analysis identified prior unifying themes and areas of commonality in recommendations for how to improve Perinatal Mental Health outcomes from a wide array of leading experts, organization reports, and expert convenings. (See Landscape Analysis for supplemental information – Mind the Gap National Report)

This analysis formed the basis for a September 2019 Mind the Gap Advisory Working Group, convened by PSI, in partnership with The Reilly Group and more than 25 national organizations and experts. Participants discussed ways to bridge the gap and build consensus on a core set of priorities, supported by specific, concrete actions to improve the mental health and well-being of pregnant and postpartum women and their babies’ development and family health.

Consensus

The Advisory Working Group collectively supported Five Shared Priorities in five critical areas.

<table>
<thead>
<tr>
<th>Awareness and Help Seeking</th>
<th>Screening and Follow Up Care</th>
<th>Access and Coverage</th>
<th>Education &amp; Training</th>
<th>Clinical &amp; Prevention Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raise public awareness of Perinatal Mental Health, including greater understanding of the importance of prevention, recognition, and treatment, and how to seek help and support for mothers and families.</td>
<td>Ensure Perinatal Mental Health screening is universal, standard, and routinely provided as part of health care delivery. Also, ensure that a positive screening includes follow-up diagnosis, referral, and access to treatment, during both pregnancy and postpartum, across all health care sectors.</td>
<td>Improve public and private access to and coverage of comprehensive prevention and integrated Perinatal Mental Health care and treatment.</td>
<td>Provide Perinatal Mental Health training for mental health and health care professionals including education on screening, referral, treatment, and support services for mothers and families.</td>
<td>Support and promote population-based research and evidence-based prevention interventions that are culturally relevant and inclusive to underserved populations and communities.</td>
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</tbody>
</table>

Figure 1: National priority areas identified based on analysis of national reports, policy statements, and convenings with experts. The Mind the Gap Advisory Working Group coalition provided input and revisions resulting in these consensus strategic priorities serving as a roadmap to improve Perinatal Mental Health.
Executive Summary

Actions
One of the most significant results from the Advisory Working Group was identifying and building consensus on specific actions to advance the five priorities as a coalition:

- Engage public and private sector partners to support and implement a national public awareness campaign on Perinatal Mental Health
- Make Perinatal Mental Health a priority for private health insurers
- Increase support for clinical training and continuing education of health care and mental health professionals, allied health professionals, and peer specialists on Perinatal Mental Health
- Increase funding for federal grant programs that address Perinatal Mental Health by reauthorizing the Health Resources and Services Administration’s Maternal Depression and Related Behavioral Disorders (MDRBD) at a higher funding level so additional organizations, states, and regions can participate
- Advocate for public policies that integrate and extend Perinatal Mental Health care to improve outcomes, with a special focus on Medicaid
- Advocate for increased federal funding to focus on translational research and the public health impact of Perinatal Mental Health
- Include affirmative language for Perinatal Mental Health in the Democratic and Republican convention platforms
- Support organizations and coalitions advocating for patient protections and mental health parity, per the Affordable Care Act (ACA), across all health plans
- Establish a national coordinating entity to advance specific Mind the Gap action items and form partnerships across sectors to promote Perinatal Mental Health as a national priority, galvanize communications, and support current partners’ best practices and policies

“PSI’s vision is for every woman and family to have access to information, social support, and informed professional care to deal with mental health issues related to childbearing. Research shows just how crucial Perinatal Mental Health is to families, children, and communities. Now, working together on the Mind the Gap Initiative, we have the commitment, strategic roadmap, and leadership to make that vision a reality.”

Ann Smith, CNM, Board President, Postpartum Support International

“Each of the Mind the Gap partners are change-makers. Working together, galvanizing shared expertise, practices, and ideas into collective action, we can amplify that change, bring it into communities and elevate it across the country. Together, we can help be the difference in the lives of mothers, children, fathers, partners, and families.”

Colleen Reilly, MPA, President, The Reilly Group
Executive Summary

Projects
The priorities and actions will be advanced through integrated projects working in coordination and collaboration with partners. Projects listed below evolved from the Advisory Working Group discussions and are designed to elevate partners’ policy efforts, best practices models, and, overall, bring greater attention to the issue at the national, state, and local level.

Education and Awareness Campaign engaging the Mind the Gap coalition:
- Informed by research and focused initially on raising awareness about Postpartum Depression among women
  - Featuring women’s lived experiences
  - Call to Action to connect and encourage help seeking
- Campaign will include tool kit with messages, social media, fact sheets, op-eds, and resources
- Campaign can be extended through national, state and community events
  - Capitol Hill Briefings
  - Conferences and Roundtables
  - Regional and State meetings
- Mind the Gap Coalition would serve to amplify the campaign through their organization’s networks and media platforms

Regional and State meetings with Mind the Gap coalition members in targeted areas. The convenings would focus on:
- Engaging a broad cross-section of stakeholders
- Building the case for the economic and public health impact of untreated and unaddressed Perinatal Mental Health
- Promoting model programs, best practices, and community resources for screening, referral, and linking to and improving access to treatment and services
- Advancing education and training for providers, allied health professionals, community stakeholders, and peer to peer specialists
- Including policy makers, payers, legislators, and other decision makers
- Galvanizing community engagement and action, and sharing resources

Advocacy and Policy Networks comprised of Mind the Gap coalition experts and other stakeholder organizations that would advance:
- Specific policy, legislation, practice, and research efforts, identified by the Advisors, to improve Perinatal Mental Health as detailed further in the Bridging the Gap section
Executive Summary

Alignment
Mind the Gap Advisory Working Group members were surveyed after the meeting to gather feedback and ensure alignment on projects to undertake as a coalition moving forward. Feedback included:

• 87% want to collaborate on a national public awareness campaign

• 91% would like to participate in or jointly convene regional/state (and national meetings) focused on advancing Perinatal Mental Health

• 71% want to advocate for focused improvements in federal funding and resources for screenings, training, access and coverage to treatment and services

• And, more than 70% want Mind the Gap to serve as the coordinating entity to advance collective impact work.
WHAT IS THE GAP?
Women

About four million women give birth each year in the U.S. Of those, at least one in seven U.S. women, or approximately 600,000 women per year, will experience perinatal depression related to a live birth. If that number is adjusted to include women who suffer a miscarriage or a stillbirth, the figure rises to about 900,000 per year. Similarly, anxiety disorders are common during the perinatal period and the reported rates are indicated to be higher, when compared to the general population.¹ By contrast, annually about 332,000 women will be diagnosed with invasive or non-invasive breast cancer as noted by the American Cancer Society.²

Multiple research studies have found that depression is most common during the perinatal period and women are more likely to develop depression during the first year following childbirth than at any point in their lives.³ ⁴ Even though there are effective treatments, less than 30 percent women who screen positive for depression and anxiety seek or receive treatment.⁵ ⁶

Unlike the more short-term (generally less than 10 days) “baby blues,” symptoms of Perinatal Mental Health disorders last more than two weeks.⁷ They have distinct and persistent symptoms and include a range of disorders: major depressive disorder, minor depression, generalized anxiety disorder, panic disorder, obsessive compulsive disorder, perinatal post-traumatic stress disorder, bipolar disorder and postpartum psychosis. These conditions are also referred to as Perinatal Mood and Anxiety Disorders (PMADs) and Maternal Mental Health (MMH) disorders.
WHAT IS THE GAP?

Perinatal depression alone ranks as the most underdiagnosed complication of pregnancy in the United States and may not manifest itself until many months after delivery.8

Women at Higher Risk

African American and Hispanic women have the highest prevalence of perinatal depression, primarily attributed to a lack of social support, access to care, and a history of trauma and prior depression.9 African American women frequently receive poorer quality care, and when care is received, it is more often fragmentary and inconsistent.

“We need to recognize that we cannot raise healthy children and have healthy families without addressing maternal mental health. We can start by making the detection, assessment and treatment of mood and anxiety disorder a routine part of obstetric care, just like any other medical illness. Let’s use diabetes as an example. All women are screened for diabetes. If they screen positive, women are started on treatment and then there is close follow-up to make sure the blood sugar is under control and mom and baby are healthy. Depression is twice as common as diabetes in pregnancy. Just like diabetes, depression affects mom and baby’s health. Despite this, depression often goes unaddressed and untreated. Mood and anxiety disorders need to be addressed just as proactively as diabetes.”

Nancy Byatt, DO, Medical Director, MCPAP for Moms

Racial disparities are further compounded by a lack of proximity to services, lack of insurance coverage, a stigma associated with mental health, and a mistrust of mental health professionals.10 For example, four-in-ten low income African American mothers do not access postpartum visits and do not receive care and support for postpartum depression and other challenges.11

“Generations of racial and gender discrimination have taken an extreme toll on Black women’s maternal health. Black women, who have much higher rates of maternal mortality, pre-term births and infant mortality are much less likely to have their perinatal depression diagnosed. The Mind the Gap Collective Impact Initiative has acknowledged the most important social determinants of maternal health and provided a forum for prioritizing how they can be addressed.”

Linda Blount, CEO & President, Black Women’s Health Imperative
WHAT IS THE GAP?

Maternal Mortality and Perinatal Mental Health

The United States has the highest rate of maternal mortality in the developed world. An analysis by the medical journal, The Lancet, found that the U.S. has a maternal mortality rate of 26.2 per 100,000 live births, more than three times greater than Canada and the overall average for Western Europe. Untreated Perinatal Mental Health disorders are a significant contributor to maternal mortality – and can increase the risk of suicide, maternal and infant death, and morbidity.

According to the Centers for Disease Control and Prevention (CDC), mental health conditions were the second leading cause of pregnancy-related death that occurred within 43 days to one year after the end of pregnancy (Figure 2). The 2018 report from the Nine Maternal Mortality Review Committees highlights “the frequency of under-diagnosis and misdiagnosis” of “maternal mental illness,” adding, “The result can be inappropriate care, potentially leading to missed opportunities for treatment and increased risk of morbidity and mortality.”

Figure 2: Maternal mental health is the second leading cause of maternal mortality from 43 days to one year after the end of pregnancy. Data adapted from CDC’s Building U.S. Capacity to Review and Prevent Maternal Deaths. 2018. Report from Nine Maternal Mortality Review Committees.

“We are all attempting to improve care, reduce suffering, and improve the quality of life for mothers. This demands a family-centered and patient-focused approach to care. As front-line providers, we believe that nurses are in key positions to screen women and improve their access to care for Perinatal Mental Health. We can also encourage women to share their experiences and optimize the level of care they need.”

Jacqueline Rychnovsky, PhD, RN, Vice President of Research and Policy and Strategic Initiatives, Association of Women’s Health, Obstetric, and Neonatal Nurses (AWHONN)
WHAT IS THE GAP?

Fathers
Fathers are at risk; estimates are that 5 to 10 percent of fathers experience postpartum depression connected to a baby’s birth, but that number rises to 24 to 50 percent when the mother experiences perinatal depression. Maternal depression is consistently the most important risk factor for depression in fathers. Much more research is needed to truly understand the scope of the problem and its effect on a child’s development.

Infants and Children
Multiple studies have found that a mother’s mental health status has a significant, long-term effect on the physical and emotional development of her infant, as well as adversely impacts mother-baby interactions. Children born to mothers who have been diagnosed with depression experience physical changes in their brain architecture. These changes are linked to negative long-term outcomes for learning and school performance, behavior, the development of future mental health issues, and overall functioning into adulthood.

“A High Cost in Health Outcomes
According to a report by Mathematica, untreated Perinatal Mental Health Disorders cost the United States an estimated $14.2 billion in 2017, and 60 percent of these costs are attributed to maternal outcomes. The average cost per mother-child pair was $32,000, with the child cost averaging $12,480 of that total over a six-year timeframe. The majority of societal costs by mother-child pair were due to increased utilization of public sector services, maternal productivity loss, and higher health care costs.

These health care costs were borne primarily by health care payers, with $2.9 billion dollars spent on maternal health expenses (including mental health) and $4.6 billion on child health expenses. For 2017 alone, Mathematica noted that the annual cost of pediatric Emergency Department visits in the United States was estimated to be slightly more than $200 million.

“Perinatal Mental Health isn’t just a women’s issue, or an infant’s issue, or a parental issue. It’s a true public health issue that impacts each and every one of us. It carries over to the workplace, to education and child development, and to the health and well-being of tomorrow’s adults.”

Wendy Davis, PhD, Executive Director, Postpartum Support International
WHAT IS THE GAP?

“Sometimes, the baby is the patient being seen in the emergency room, but the mother also needs care. Especially in the pediatric Emergency Department, we need to be considering the mothers’ (and families) physical and mental health.”

Lenore Jarvis, MD, Pediatric Emergency Medicine Physician, Children’s National Health System

Adverse Workplace Impact
Beyond the mother’s suffering, adverse child developmental issues, and high health care utilization, Perinatal Mental Health disorders can adversely impact the workplace.

In 2018, according to the Bureau of Labor Statistics (BLS), about 65 percent of mothers with children under age six worked, and 75 percent of those employed mothers worked full-time.\textsuperscript{21} New mothers are also a significant component of the current workforce. BLS reports that one in four women returns to work ten days after giving birth, and approximately 43 percent of women return to work within one month. Untreated maternal depression can affect the mother’s — and father’s — performance at work, as well as increase absenteeism and disability and decrease both productivity and overall workforce participation.\textsuperscript{20}
WHAT IS THE GAP?

A National Deficit Resulting from an Action Deficit, a Treatment Deficit, a System Deficit, and a Dollar Deficit:
The Mind the Gap Landscape Analysis and observations by the Advisory Working Group identified several key deficits that contribute to unaddressed and untreated Perinatal Mental Health disorders. While the purpose of the report is not to detail all deficits, key ones are noted here.

An Action Deficit
Despite the numbers and the wide scope of impact, Perinatal Mental Health receives limited national attention and limited funding. There is a lack of public awareness, professional education, access to treatment and care, and stigma associated with the issue. Even though national and state health policies are increasingly focused on improving maternal mortality and morbidity, there is a gap in prioritizing maternal mental health conditions as a major contributing factor.

Despite multiple calls for greater attention to Perinatal Mental Health, there has yet to be a comprehensive national action plan to address these disorders. By contrast, other nations including Great Britain, Australia, and Ireland have adopted or are in the process of implementing comprehensive Perinatal Mental Health care approaches and greater awareness.

A Treatment Deficit
The most common starting point for identifying possible Perinatal Mental Health disorders is through screening. However, screening is not universal or standard, and referrals, diagnosis, and access to treatment are not always coordinated or provided. Even though national professional organizations have issued guidelines and support screening and treatment, and there are multiple, effective screening tools available, universal screening and access to treatment are not routinely provided across various health care sectors.
Importantly, treatment does not always follow a positive screen or diagnosis. In fact, less than 30 percent women who screened as positive for depression and anxiety receive treatment. In addition, the silo system governing the delivery of maternal and child health care can add obstacles to screening, diagnosis, and treatment of Perinatal Mental Health disorders.

“A System Deficit
Access to treatment and care is not universal, fully covered, or always reimbursed. Thus, while individual states, communities, and health care systems are working to develop or implement Perinatal Mental Health programs and practices to meet the need, these options do not yet exist in all public and private health insurance plans, in all states, or within a national framework, unlike other maternal health conditions, such as, for example, gestational diabetes, leaving many mothers and families at-risk.

In addition, under the current U.S. healthcare system, some public and private health payers limit access to or do not cover services and treatment for Perinatal Mental Health disorders or relegate mental health care to a restricted or lesser coverage status.

Another obstacle is regulatory and institutional. Treatment, service, and billing regulations may prevent pediatricians and other infant healthcare providers from directly participating in a mother’s care. Additionally, many health care professionals may lack training in, education about, resources for, and the means to follow-up regarding Perinatal Mental Health disorders.

“We know from other efforts to innovate in mental health and substance use care that it helps to start small, with test models. We need to have ways to gather patient and clinician feedback to make adjustments. And we need to find ways to have training and assistance in best practice available for clinicians and patients. It’s also important we identify ways to reach women and families and make care convenient for them to access.”
Michelle Dirst, Director, Practice Management and Delivery Systems, American Psychiatric Association
The American College of Obstetricians and Gynecologists (ACOG) now recommends that all obstetrician-gynecologists and obstetric care providers screen patients once during the perinatal period for depression and anxiety and, additionally, for mood and emotional well-being during a comprehensive follow up no later than twelve weeks after a birth.  

A Dollar Deficit
Finally, Perinatal Mental Health receives limited federal research dollars in comparison to other women’s health issues with a similar population prevalence. For example, according to the landscape analysis conducted by Mind the Gap, in 2017 the two major federal research centers, National Institute for Health (NIH) and Centers for Disease Control (CDC) (Figure 3), spent $3.3 billion on women’s heart disease research, which affects one in five women; $1.4 billion for breast cancer research, which affects one in eight, and Lupus, which affects one in 200 women, received $197 million. Perinatal Mental Health, which has a higher prevalence rate than breast cancer and lupus, received only $54 million in federal research dollars.

“Research show us how vital a mother’s well-being is to the healthy development of her child. To prioritize children, we also have to prioritize the mental and physical health of their moms. With nearly four million babies born each year, we have a lot of work to do so that every baby can have the best possible start.”

KJ Hertz, Director, Federal Affairs, March of Dimes

Figure 3: Perinatal mental health funding does not match the crisis today. Total grant funding by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) for fiscal year 2017 for heart disease, breast cancer, lupus, and perinatal mental health is compared above, with the prevalence information. Federal RePORTER database information was used by The Reilly Group to conduct the funding analysis.
BRIDGING THE GAP

Mind the Gap: A Strategic Roadmap to Address America’s Silent Health Crisis: Untreated and Unaddressed Perinatal Mental Health Disorders, Led by Postpartum Support International
There is significant evidence that Perinatal Mental Health is a national public health issue seriously impacting the health and well-being of mothers, infants, fathers, partners, families and the broader community. Leading national organizations have issued guidance and statements on screening and follow-up care, national groups have convened in dialogue to discuss critical areas resulting in reports, and some key states have issued recommendations that are paving the way for change.

However, still absent from these important efforts is a national framework and strategic action plan.

In 2019, Postpartum Support International and The Reilly Group conducted an in-depth analysis of the available data and reports to begin the process of framing a collective response. The analysis included researching and reviewing published articles and leading organizations’ recommendations and statements, as well as national and state report priorities and findings (See Landscape Analysis). It also included in-depth interviews with more than 40 experts from major organizations to gain insights on priorities and effective policies and programs. Many of these experts formed the Mind the Gap Advisory Working Group (See List of Advisors).

This landscape analysis was instrumental in identifying a set of draft priorities that formed the basis for a broad group discussion during a day-long convening on September 27, 2019 in Washington, DC.

The central goal of the Advisory Working Group was to build consensus and galvanize leading organizations around a set of key priority areas and specific actions to undertake, as a group, to advance Perinatal Mental Health.

Additionally, the Mind the Gap convening provided an opportunity for organizations to share their programs and best practices, so that the larger group could identify steps where the Mind the Gap Initiative can assist and collectively support important current efforts that are already advancing and improving outcomes for perinatal and maternal mental health.
BRIDGING THE GAP

Five Shared Priorities
The Advisory Working Group refined and agreed upon five shared priorities to advance Perinatal Mental Health. Notably, each priority is supported by research, prior convenings, and the work of leading national and state organizations. Each priority also generated specific, consensus-built concrete actions, enumerated below.

Awareness and Help Seeking:
Raise public awareness of Perinatal Mental Health, including greater understanding of the importance of prevention, recognition, and treatment, and how to seek help and support for mothers and families.

“Collectively, we need to raise public awareness especially among women. Through our organization, we can reach millions of women (and providers) giving them information, tools, and connections to hope and helpful resources in the community.”
Beth Battaglino RN, CEO & President, HealthyWomen.org

Screening and Follow-up:
Ensure Perinatal Mental Health screening is universal, standard, and routinely provided as part of health care delivery. Also, ensure that a positive screen includes follow-up diagnosis, referral, and access to treatment, during both pregnancy and postpartum, across all health care sectors.

“Screening for depression and anxiety—similar to other routinely recommended screenings and tests—should be part of perinatal care for all women.”
Arlene Remick, Program Director, American College of Obstetricians and Gynecologists

Access and Coverage:
Improve public and private access to and coverage of comprehensive prevention and integrated Perinatal Mental Health care and treatment.

“Screening standards must include follow-up diagnosis, referral and treatment if a screen is positive. We’re committed to working together to ensure these next steps to care are available for people in need. As a leader in caring for moms and babies, we will look to provide more training, protocols, and guidance for our nurse midwives to address the need. We also look forward to supporting federal and state issues that seek to expand funding and access to mental health services such as Medicaid coverage to 365 days.”
Sara Mertz, Certified Nurse Midwife, Chair, Perinatal Mental Health Task Force, American College of Nurse-Midwives
BRIDGING THE GAP

Five Shared Priorities continued

Education and Training:
Provide Perinatal Mental Health training for health care professionals, including education on screening, referral, treatment, and support services for mothers and families

“Educational and training opportunities should be increased for all clinicians. The urgency and importance of addressing perinatal mental health, need to be stressed. Providing pathways to use technology, case-based learning, and other cost-effective and time-efficient methods can help to increase the capacity and competency of all health care providers. At the AAP, we have developed innovative methods that support continuing medical education and training.”

Debra Waldron, MD, MPH, FAAP, Senior Vice President, Healthy and Resilient Children, Youth, and Families, American Academy of Pediatrics

Clinical and Prevention Research:
Support and promote population-based research and evidence-based prevention interventions that are culturally relevant and inclusive to underserved populations and communities

“There is so much important research we need and can do, at all levels, to increase our understanding of maternal mental health, including appropriate funding to conduct the research.”

Samantha Meltzer-Brody, MD, Past-President, Marcé Society of North America, Assad Meymandi Distinguished Professor and Chair, Department of Psychiatry, The University of North Carolina at Chapel Hill
Guiding Principles

The Advisory Working Group established a set of principles to anchor and guide the Mind the Gap work. The principles are designed to ensure that Mind the Gap priorities and actions are sustainable, inclusive, and develop the widest community and strongest coalition behind their implementation:

• Increase investment by public, philanthropic, and private sector organizations to fund and improve Perinatal Mental Health: screening, access to care and treatment, education, and public awareness
• Advance collective impact activities and partnerships that ensure Perinatal Mental Health is a national priority
• Ensure programs and practices are equitable, culturally relevant, inclusive, and tailored to the needs of diverse communities

“Mind the Gap is an important initiative and AMWA is looking forward to working in coalition on the strategic plan of priorities and actions. We have AMWA members who are experts in women’s mental health providing leadership in the military and through research and direct services in health systems.”

Eliza Chin, MD, Executive Director of the American Medical Women’s Association
**BRIDGING THE GAP**

**Actions**

Central to developing a strategic roadmap is identifying specific actions that will advance Perinatal Mental Health and the Five Shared Priorities. The Mind the Gap Advisory Working Group focused on ways to use the power of collective action as a multiplier to achieve real and lasting change.

A key element of the convening was facilitated break-out sessions, where participants brainstormed ways to address the central issues and needs. These sessions grouped the participants by specialty, allowing them to have in-depth discussions and propose specific, concrete actions to improve Perinatal Mental Health and leverage existing policies and legislation, build on evidence-based programs, and launch national advocacy and awareness. Below are the specified actions and details.

**Action: Engage public and private sector partners to support and implement a national public awareness campaign on Perinatal Mental Health**

The Advisory Working Group agreed that a national public awareness campaign is a critical component to elevate the issue and its importance. The group concluded that campaign efforts should engage public and private sector partners and focus (initially) on raising awareness with women of childbearing age.

Central tenets of the campaign, as identified by Advisors, include:

- Universal language and messages
- Diversity, featuring women from all walks of life discussing their lived experiences, giving voice to their struggles, and hope for help
- Research both evidenced-based terminology and statistics, including direct engagement with and insights from women
- Outreach to a broad coalition of partners, including health organizations, experts in the field, and well-known public figures, influential nationally and locally
- Utilize diverse channels and platforms, including traditional and social media, and involve micro-influencers and champions
- Engage local communities where women and families live, through a “roadshow” to raise awareness and connect women and families to support and resources.

“I experienced postpartum depression and anxiety after my son (the second of my three children) was born. We had a very scary C-section, he wanted to be held all the time and refused to take a bottle, and I was exhausted and overwhelmed as I struggled to care for a newborn and a toddler. All I wanted was to find somewhere that I could sleep for a year or two. I told my husband I wanted a divorce, truly believing my family would be better off without me. I didn't know what I was experiencing was treatable. Our little family struggled for six months until my husband finally found a doctor who understood what I was going through and started me on the path to recovery. I decided during this dark time in my life that I needed to do something to help other women so they wouldn’t suffer needlessly as I did.”

*Adrienne Griffen, MPP, Executive Director, Maternal Mental Health Leadership Alliance*
While approximately 50 percent of pregnancies in the United States are covered by the federal government’s Medicaid program, the other half are covered by private insurers. The Advisory Working Group heard presentations from and discussed further engaging private sector partners to recognize the vital importance and improved outcomes of investing in Perinatal Mental Health.

Dignity Health (now known as CommonSpirit) and HCA Healthcare, two organizations that participated in the meeting, have identified Maternal Mental Health as top priorities. For example, CommonSpirit is implementing education and training programs for providers, patients, and families. They are developing Universal Screening toolkits for hospitals and engaging their communities in collaborations.

These models and other healthcare models identified in the landscape analysis are working to deliver effective care. The Advisors discussed the importance of engaging health care organizations and systems (such as hospitals) with specific actions including:

- Promoting best practices and wide-scale implementation of integrative health care system models for Perinatal Mental Health care and treatment during pregnancy and postpartum through specific efforts in collaboration with hospital systems and insurers
- Working with and advocating for State Insurance Commissioners to define and include perinatal mental health as an essential health benefit (EHB)
The Advisory Working Group agreed that a central issue to improving outcomes in Perinatal Mental Health is to involve many sectors of the healthcare system in understanding and intervening to prevent and treat these disorders. Therefore, Perinatal Mental Health training and education needs to include multiple providers who serve pregnant women and mothers, spanning the continuum from OB/GYN providers, nurse midwives, and lactation consultants to peer support, nurse practitioners, NICU nurses, medical assistants, general practitioners, pediatric providers, EMTs, Emergency Department personnel, social workers, and mental health professionals including psychiatrists.

The Advisory Working Group identified several factors to consider in education and training initiatives, such as the woman’s environment, her culture and language, and making sure that training and education are family-centered and involve fathers and partners. Training should also consider implicit bias, both gender and cultural, and trauma-informed education.

"Increasing the confidence of all providers to treat – from nurse midwives to psychiatrists – is an important national focus for improving perinatal mental health. Disseminating information through all of our organizations as well as making it easier to access training and technical support will be game changers. And always, we want to ensure families are an important part of the treatment team and education effort.”

Jennifer Payne, MD, Director of Women's Mood Disorders Center at Johns Hopkins Medicine
BRIDGING THE GAP

Action continued

The Advisory Working Group proposed three initial efforts centered on training and education:

• Engage the American College of Graduate Medical Education (ACGME) to include education regarding Perinatal Mental Health in medical school and post-graduate education, and advance Continuing Medical Education (CME) in Perinatal Mental Health for health care providers. Promote clinical residency training with a Perinatal Mental Health specialty.

• Partner with professional and advocacy organizations (e.g. Mental Health America, Recovery Inc, and other member organizations in the Mental Health Liaison Group) to develop and promote training for peer support specialists around the issues of Perinatal Mental Health.

• Advance and expand Postpartum Support International’s Perinatal Mental Health Certification (PMH-C), which provides training and certification for mental health professionals and allied health professionals.

“PSI provides a range of evidence-based trainings for frontline providers and other mental health and health care professionals in person and via e-learning training webinars. We’ve trained hundreds of thousands of professionals interacting with millions of women. Our trainings incorporate the culture of the organizations we work with as well as the community. We know the communities, because we are in communities across the county. Also, PSI can fortify training with on the ground local supports and resources for moms and families.”

Wendy Davis, PhD, PMH-C, Executive Director, Postpartum Support International

“At Mental Health America we look forward to working with Mind the Gap to expand Perinatal Mental Health training and support health professionals as well as engage peers so they can be part of the clinical team. Peers are some of the best bridge builders we have. Peer specialists can say, I know what this is about, I’ve walked in your shoes, here’s how to get help and continue to be supported.”

Debbie Plotnick, MSS, Vice President for Mental Health and Systems Advocacy, Mental Health America
BRIDGING THE GAP

**Action:** Increase funding for federal grant programs that address Perinatal Mental Health by reauthorizing the Health Resources and Services Administration’s Maternal Depression and Related Behavioral Disorders (MDRBD) at a higher funding level so additional organizations, states and regions can participate.

The Advisory Working Group agreed Federal health programs have a vital role in addressing Perinatal Mental Health, including the U.S. Department of Health and Human Services’ Health Resources and Services Administration (HRSA), home to the Maternal and Child Health Bureau, which focuses on pregnant women, mothers, families, and children.

HRSA’s Maternal Depression and Related Behavioral Disorders is one of the most significant Federal programs for Perinatal Mental Health and builds on successful state models (i.e. MCPAP for MOMS program in Massachusetts).

The MDRBD’s purpose is to expand health care providers’ capacity to screen, assess, treat, and refer pregnant and postpartum women for maternal depression and related behavioral disorders, such as anxiety and substance misuse, including in rural and medically underserved areas, and to increase access to affordable, culturally, and linguistically appropriate treatment and recovery support services.

Currently, the MDRBD awards provide funding for (only) seven states and regions to expand psychiatric consultation, care coordination support, and training to front-line providers, along with programs such telehealth consults.

Thus, building on and increasing funding for the grant program would be an essential action to advance collectively to ensure Perinatal Mental Health is a national priority.

> “These awards have a five-year span because we want recipients to have time to establish systems that will lead to real change. HRSA’s long-term goals for this program are to achieve universal behavioral health screening in target areas; increase early detection, assessment, treatment and referral; and connect and provide evidence-based treatments and recovery supports locally or via telehealth.”

_Dawn Levinson, MSW, Behavioral Health Lead, Health Resources and Services Administration_
The Advisory Working Group discussed the role of telemedicine consultation services. Currently, there are several models: Postpartum Support International’s perinatal psychiatric consult line and state maternal mental health psychiatric consult lines such as Wisconsin's Periscope Project and Massachusetts-based MCPAP for Moms program. These programs have a multiplier effect in reaching and educating more primary care and psychiatric providers. Easier access for health care providers to Perinatal Mental Health experts and technical support are vital components to improving care delivery.

Another key action the Advisors proposed was to advocate for federal, state, and private sector funding and support for healthcare workforce development and training such as Perinatal Mental Health training and certification.

“The Periscope Project services have a multiplier effect. We don’t just impact one patient, instead the education and information relayed to a health care provider can be used in caring for their entire population.”

Christina Wichman, DO, Medical Director, The Periscope Project
Action: Advocate for public policies that integrate and extend Perinatal Mental Health care and improve outcomes, with a special focus on Medicaid

While improving private insurance coverage is a critical action, the Advisory Working Group noted that there are specific policy and program changes to support better access to and coverage for mothers and families that receive their healthcare funds through government insurance programs. Approximately 50 percent of all deliveries are covered via Medicaid, the state-federal insurance program.

Policy experts attending the Advisory meeting had a robust discussion on Medicaid policies and legislative efforts. Following the passage of the Affordable Care Act (ACA) in 2014, women had guaranteed access to maternity and childbirth coverage for 60 days postpartum. After 60 days, individual states decide whether eligibility for Medicaid coverage is continued or extended for new mothers. The Advisory Working Group recommended five policy and legislative efforts to improve care and outcomes for Perinatal Mental Health:

- Extend Medicaid coverage for one year postpartum
- Expand Medicaid coverage in non-expansion states
- Encourage states to utilize Medicaid’s Early and Periodic Screening, Diagnostic and Treatment (EPSDT) reimbursement for postpartum screening of moms whose children are enrolled
- Enhance Title V (the Social Security Administration maternal and child services block grant) to include a focus on women’s maternal mental health

“Increasing investments in Medicaid and our public health infrastructure, including through extending Medicaid coverage to 12 months postpartum and providing additional funding to critical programs like the Title V Maternal and Child Health Services Block Grant and the maternal depression grant program at HRSA’s Maternal and Child Health Bureau, will go a long way towards ensuring that women and families have the supports and services they need before, during, and after pregnancy. The return on our federal and state investments is clear: healthier moms, healthier babies, and healthier communities.”

Alyson Northrup, MS, Associate Director for Government Affairs, Association of Maternal & Child Health Programs

“Depression or other mental health disorders often affect women beyond the 60-day coverage limit imposed by some states. Extending Medicaid coverage to one year postpartum is a sound policy – it allows women to access the care they may need, it makes sense economically, and it ensures quality care. As an organization, we advocate for health professionals, mothers, and babies, and also to ensure that access is protected and strengthened.”

Kathryn Schubert, MPP, Chief Advocacy Officer, Society for Maternal-Fetal Medicine
While federal agencies conduct research and collect information on a myriad of disorders surrounding maternal health, in the area of Perinatal Mental Health, significant gaps remain in data collection and funding for both clinical and prevention research. When compared to other, similarly prevalent conditions that affect women such as breast cancer and heart disease, funding levels for Perinatal Mental Health are particularly low.

Members of the Advisory Working Group discussed advocating to address these discrepancies and increase dedicated research funding on Perinatal Mental Health for the National Institutes of Health, the Centers for Disease Control and Prevention, and other relevant federal agencies. Important areas in need of additional research study include:

- Prospectively identifying women at-risk
- Assessing and disseminating evidence-based prevention programs and clinical care models
- Better understanding of healthcare providers’ systems for follow-up on positive screens for Perinatal Mental Health disorders

Overall, funding is needed for broad, population-based research, including epidemiological studies, to better understand who suffers from Perinatal Mental Health disorders, and the prevalence of these disorders among those screened, as well as which women who screen positive are referred for and have access to treatment, and, finally, which ones within that group are adequately treated to remission.

“Having clearly articulated research priorities will allow what we learn from research to be translated into effective practices.”

Deborah F. Perry, PhD, Director of Research and Evaluation, Professor, Center for Child and Human Development, Georgetown University

“We need to understand which women are being screened, referred for treatment, able to access appropriate treatment, and finally, are treated to remission of symptoms. We also need to understand how to prospectively identify those women who are at increased risk to prevent suffering.”

Samantha Meltzer-Brody, MD, Past-President, Marcé Society of North America, Assad Meymandi Distinguished Professor and Chair, Department of Psychiatry, The University of North Carolina at Chapel Hill
The group discussed the importance of engaging policy and political leaders to ensure Perinatal Mental Health is a national priority. This requires gaining the commitment from political leaders to recognize the public health urgency and impact and to support policy and programs that improve awareness and access to prevention, screening, and treatment.

Mental health should be included as a priority in the upcoming Democratic and Republican convention platforms, and inclusion of Perinatal Mental Health, particularly as it relates to the broader crisis in maternal and fetal mortality, would give added impetus to policy makers to address this crucial resource and coverage gap. In a tightly contested election year, eliciting bipartisan support for this under-addressed health issue would help elevate the national conversation around Perinatal Mental Health.
The vital issue of Perinatal Mental Health cannot be adequately addressed if mental health care is not recognized as a priority by health systems and insurance organizations. Thus, ensuring that mental health care has parity in coverage with physical health care — and has strong patient protections — must be included in any strategic action plan.

The Advisory Working Group agreed that the Mind the Gap Initiative and its advisors can offer support to the many policy and advocacy organizations that have prioritized and are working on the frontlines to protect the language and benefits of the Affordable Care Act, especially including access and parity to mental health care for all mothers and families. National Alliance on Mental Illness (NAMI) and Mental Health America (MHA) have been some of the leading organizations to advocate for and protect Mental Health Parity.

Mental Health America has stated in its Policy Position Statement #49 that: “Screening for perinatal mood and anxiety disorders and follow-up care should be a required element as part of cost-effective health home and general medical and mental health integration in all health plans.”

“Policy change is one major way we can make a difference in the lives of people living with mental health conditions and their families. NAMI advocates at the state and federal level for protecting people’s access to treatment and services; attaining mental health parity and securing better funding for research. We want to ensure families have access to the mental health care they need and deserve. All individuals and families affected by mental illness can build better lives if we commit to ensuring access, education, support, and care.”

Jennifer Snow, Director, Public Policy, National Alliance on Mental Illness (NAMI)
Action: Establish a national coordinating entity to advance specific Mind the Gap action items and form partnerships across sectors to promote Perinatal Mental Health as a national priority, galvanize communications, and support current partners’ best practices and policies.

The Advisory Working Group agreed that there has been excellent work done by advocacy and professional organizations, health systems, and states, but there is a significant need for a coordinating entity to align and advance a strategic action plan, national messaging, and coordinating and multiplying efforts, while building public-private partnerships for Perinatal Mental Health.

More than 70 percent of the Mind the Gap Advisory Working Group supported having the Mind the Gap Initiative serve as the national coordinating entity.
MIND THE GAP – CALL TO ACTION

Undiagnosed and untreated Perinatal Mental Health disorders are a silent health crisis in the United States, deserving national recognition and action to save lives and improve the health and wellbeing of America’s mothers, babies, fathers, families, and the community.

Postpartum Support International is proud to be working with a coalition of partners who have set forth a well-researched and community informed blueprint of national priorities and actions that seek to turn the tide on the crisis. We stand for increasing research and funding and improving awareness and access to prevention, education, screening, diagnosis, treatment and support services for pregnant and postpartum women and their families.

Let’s do this! Join us and millions of others to elevate and ensure that the mental health and well-being of mothers, babies, and families are in the forefront – no longer silent – and that we collectively open paths to health and wellness.
MIND THE GAP – ADVISORY WORK GROUP

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Invited (unable to attend)
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- Kate Berry, Senior Vice President, Clinical Affairs and Strategic Partnerships America's Insurance Health Plans (AHIP)
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- Tiffany Moore Simas, MD, MPH, Med, FACOG, Medical Director, Lifeline4Moms
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Mind the Gap: A Strategic Roadmap to Address America’s Silent Health Crisis: Untreated and Unaddressed Perinatal Mental Health Disorders, Led by Postpartum Support International
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**Sage Therapeutics** – committed to discovering, developing and delivering novel medicines to transform the lives of patients with life-altering disorders of the central nervous system (CNS). Sage is opening doors to new ways of thinking about treating disorders of the brain.

**Taking Health Global** – a 501(c)3 non-for-profit organization whose mission is to advance mental health awareness and work in partnership with a broad community of health and wellness organizations.

**Baby Dove** – the baby care brand from Dove, featuring products to replenish essential moisture and nutrients in baby’s skin. At Baby Dove, we know motherhood is beautiful…but hard. Baby Dove envisions a world in which all parents have the support they need to care for their babies with confidence, and this mission carries across our products, campaigns and actions for real parents.

**Postpartum Support International** – individual PSI supporters, members, and volunteers that include mothers, fathers, and families with lived experience who volunteer to build awareness and education.
CONTRIBUTORS
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The report is produced by Colleen Reilly, MPA, Monica Mallampalli, PhD, Lyric Winik, MA, and Alexis Oriel of The Reilly Group, and Wendy Davis, PhD, PMH-C, for Postpartum Support International and its Mind the Gap Initiative.

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WHY WE CHOSE MIND THE GAP
WHY WE CHOSE MIND THE GAP

You might be wondering why we chose the name “Mind the Gap.” It conjures up a somewhat famous phrase that is said in the London Underground warning people who use the subway to mind the gap between the train and the platform.

The name though also captures the gap that currently exists in our nation’s understanding of the connection and critical role that a mother’s mental health and wellbeing play in her own health and mortality, the father or partner’s health, and the physical, emotional, and social development of her baby and children.

Unaddressed or NOT minding the gap means unrealized hope and help, lack of access to treatment, poorer health outcomes, and higher health care costs to families and communities.

If we as a nation want to reduce maternal mortality, give babies a healthy start on life, give help and hope to mothers, fathers and families we must mind the gap and focus efforts on integrating perinatal mental health into the health of our nation.
ABOUT PSI & THE REILLY GROUP
PSI is the world’s largest non-profit organization dedicated to helping women and families suffering from perinatal mood and anxiety disorders, including postpartum depression. PSI was founded in 1987 to increase awareness and support public and professional communities to address the mental health risks and difficulties during pregnancy and postpartum. PSI offers support, reliable information, best practice training and certification, and more than 400 volunteers in all 50 U.S. states and more than 40 countries around the world. Working together with its volunteers, providers, researchers, legislators and other stakeholders, PSI is committed to eliminating stigma and ensuring that compassionate and quality care is available to all families.

The Reilly Group is a public affairs firm dedicated to moving the dial on issues, policies, programs, or products by advancing solutions that impact some of our greatest societal challenges. Based in Washington, DC, and working across states, the firm is nationally recognized for its expertise in engaging communities and advancing health issues: women’s health, children and adolescent health, mental health, public health, and wellness. The Reilly Group works with public organizations, foundations, government, and private sector organizations to create, implement, and managing strategic initiatives from the conceptual stage to fully scaled initiatives at the community, national and international level. The initiatives have resulted in driving and building awareness of health issues, advocating for and improving access to treatments, facilitating partnerships, and advancing policy and legislation.

The Reilly Group works extensively in states including California and Colorado and has expertise in building and implementing initiatives that include advocacy, communications, community engagement, coalitions and partnerships, media, marketing, programs, policy, research, strategic planning, and convenings.
RESOURCES FOR FAMILIES (NO COST)

- **PSI Website** – Provides support, education, local resource information to more than 100,000 visitors a year
- **800.944.4PPD (4773)** – PSI’s toll-free HelpLine, in English and Spanish, rapidly refers callers to appropriate local resources including emergency services
- **PSI Support Coordinators** – PSI support coordinators provide phone and email help and access to information including trained perinatal mental health specialists for families and communities in all 50 U.S. states, Canada, and Mexico, and more than 40 countries around the world
- **Online Support Groups** – Led by trained PSI facilitators, in English and Spanish, every week
- **PSI Educational DVDs** – for families and providers
- **Free Phone “Chat with the Experts”** – First Mondays for Dads and every Wednesday for Moms

TRAINING, TECHNICAL ASSISTANCE, & SERVICES FOR PROVIDERS, PUBLIC AND PRIVATE ORGANIZATIONS

- **Frontline Provider Trainings** – Training via webinar or onsite that equips frontline providers with the necessary skills to assess and support patients with perinatal mental health complications and connect individuals with resources for additional needs. CMEs and CEs approved.
- **Perinatal Psychiatric Consult Service** – An expert service provided to medical professionals who have questions about mental health care related to pre-conception, pregnant and postpartum patients. Call 800-944-4773, ext. 4 to make an appointment with PSI’s perinatal psychiatrists.
- **Perinatal Mental Health Trainings and Certification** – for medical and mental health providers, affiliated childbirth professionals, volunteer advocates, hospitals, health care organizations, and state, county and city agencies.
- **Technical Assistance & Support** – Expert consultation, or direct access, on developing perinatal mental health capacity and psychiatric consult lines
- **Online Perinatal Mental Health Provider Directory** – PSI’s no cost directory of perinatal mental health specialists
Mind the Gap: A Strategic Roadmap to Address America’s Silent Health Crisis: Untreated and Unaddressed Perinatal Mental Health Disorders, Led by Postpartum Support International


Mind the Gap is a Collective Impact Initiative led by Postpartum Support International, comprised of women leaders with lived experience, and other leaders from professional and advocacy organizations representing pediatric health, public health, maternal mental health, mental health, women’s health, as well as academia, healthcare organizations, major medical centers, and philanthropy – all working toward improving Perinatal Mental Health. (See Advisory Work Group List)