

How the Patient Voice Informed New Hampshire's Maternal Health Strategic Plan

New Hampshire Perinatal Quality Collaborative
April 2026

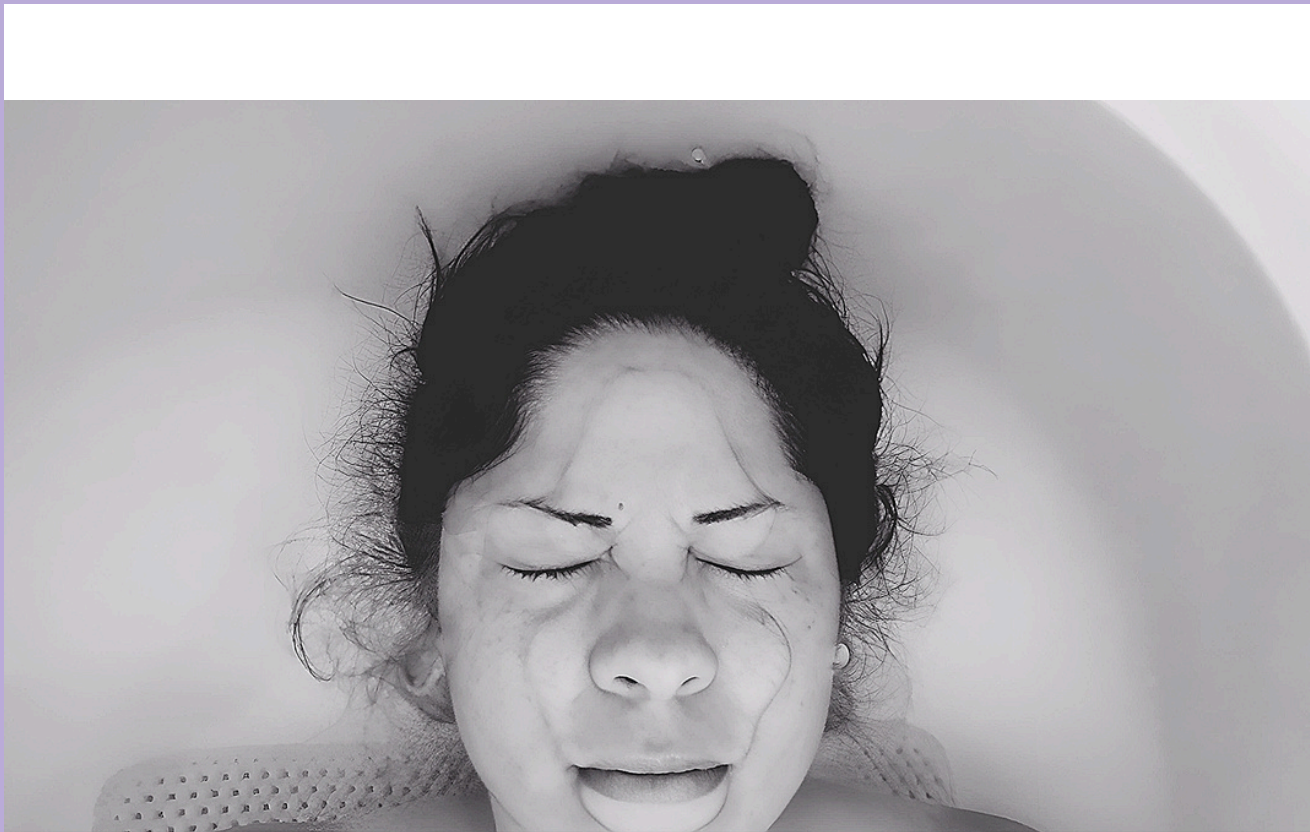


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Exhausted and Overwhelmed: A mother in the North Country struggles to find solace in the midst of prenatal and postnatal care challenges. The isolation and lack of access to resources weigh heavily on her, leaving her feeling drained and helpless... -Rose Toner



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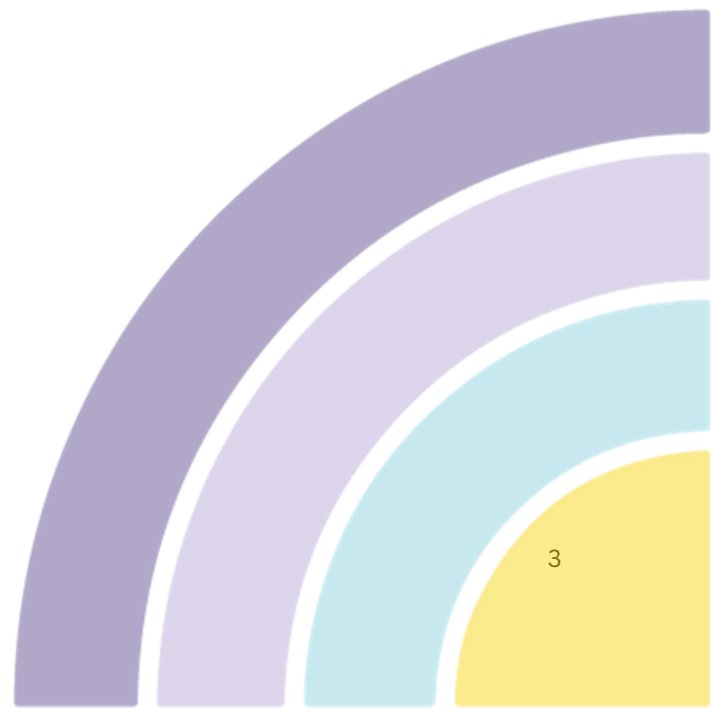
Report Prepared by

How the Patient Voice Informed New Hampshire's Maternal Health Strategic Plan
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A Statement of Gratitude

We are grateful for the voices of the patients, clinicians, and community members willing to share their stories and experiences represented in this report. The members of the Maternal Health Task Force and the NHPQC coalitions will continue to learn from these stories as we strive to create change and improve maternal and infant health.

We also deeply appreciate the commitment of maternal health researchers (see page 13 for a full list contributors) across the state who work to better understand the perinatal experience. None of this work would be possible without the commitment and expertise of these colleagues.



Executive Summary

The New Hampshire Perinatal Quality Collaborative (NHPQC) was established to improve perinatal care statewide by centering patient and community voices. Our vision: all birthing patients feel emotionally, psychologically, and physically safe while receiving caring, respectful, high-quality care before, during, and after birth. Achieving this requires understanding current patient experiences and actively collaborating with patients, families, and communities to co-create change.

New Hampshire's maternal mortality and severe maternal morbidity data reveal worse outcomes for specific populations—those in rural areas, communities of color, people living with substance use disorder, and Medicaid recipients. The data also show that all pregnant and postpartum patients face barriers affecting when, where, how, and from whom they receive care—or whether they receive care at all. Understanding these experiences is essential to addressing these barriers.

The NHPQC, and collaborating researchers, used qualitative research methods to capture patient voices. These findings shaped the priority goals, strategies, and initiatives in our co-created Maternal Health Strategic Plan (see Table 1 for impact breakdown).

Many research participants became actively involved in NHPQC's work—joining the Task Force, contributing to the Strategic Plan, or participating in initiatives across the state. We will continue this collaborative work as we strive to ensure respectful maternity care for all, with improved access and outcomes statewide.

Table 1. Key Findings of the Patient Voice Research and its integration in the MHSP.

Patient Voice Research: Key Findings	Maternal Health Strategic Plan
<ul style="list-style-type: none"> • Shared decision-making continues to be lacking in maternity care. • People feel that their needs, voices and expertise are not always heard by perinatal providers. 	<p>Enhance provider-patient relationships through improved communication and power dynamic</p>
<ul style="list-style-type: none"> • A culture of caring begins by listening to the patient and hearing their experiences 	<p>Co-create with those with lived birthing experiences to provide vital info/ insights for provider education to inform improvement efforts</p>
<ul style="list-style-type: none"> • Improved community connection helps patients to make better informed decisions 	<p>Expand culturally and linguistically inclusive training pathways to create a workforce reflective of the communities</p>
<ul style="list-style-type: none"> • Though resources exist in NH communities, they are unevenly distributed and poorly disseminated. • Patients and providers are not always aware of available resources 	<p>Create and support a sustainable resource and communication system for birth communities and providers</p>
<ul style="list-style-type: none"> • Patients need better support in their homes. • Patients feel isolated, especially in the postpartum period 	<p>Enhance home visiting and support for all postpartum patients</p>
<ul style="list-style-type: none"> • Peer relationships are highly valued as a way to reduce stigma and isolation 	<p>Expand network for peer-to-peer connections and support during pregnancy and parenting</p>
<ul style="list-style-type: none"> • CHWs and Doulas help bridge families to providers/health system 	<p>Support holistic transition into parenthood</p>

Introduction & Objectives

The New Hampshire Perinatal Quality Collaborative formed to improve maternity care in the state by centering the patient and community voice. New Hampshire's maternal mortality and severe maternal morbidity data highlights significantly worse outcomes for rural populations and communities of color. The data also indicate that pregnant and postpartum patients face several barriers to care. These barriers influence when, where, how, and from whom patients receive care—or whether they receive it all.

Understanding the patient's voice is central to addressing these barriers. To capture the patient voice, we and our collaborating researchers used qualitative research methods such as Emotional Journey Mapping, Photovoice, surveys, focus groups, and interviews. The results of this research highlight the many factors that shape a patient's experience, their willingness to engage in care and influence outcomes. Breakdowns in communication, lack of appropriate services due to distance or insurance payor, difficulty accessing mental health services, provider shortages, hospital closures and the need for more community engagement were common themes across the research presented in this report.

This report serves a few purposes: it provides a snapshot of the current experience of pregnant and postpartum patients in the state while highlighting the role of the patient voice and its connection to the mission of the NHPQC. Finally, the report shows how the data has informed the Maternal Health Strategic Plan with recommendations for improving patient care and experience in the state.

Background

The New Hampshire Perinatal Quality Collaborative

Dartmouth-Health (DH) and the NH Department of Health and Human Services (NH DHHS) Maternal and Child Health (MCH) launched the NHPQC in March 2024 to develop a community-based model focused on improving outcomes for populations disproportionately impacted by maternal mortality and severe maternal morbidity (PDI). Between 2019-2023, the New Hampshire Maternal Review Committee (MMRC) found that 79.1% of maternal deaths in the state were preventable.¹

In response to these findings and the committee's recommendations to improve outcomes, DH began a 12-month planning process for the NHPQC. DH utilized its previously established network of the Northern New England Perinatal Quality Improvement Network (NNEPQIN) to engage stakeholders to join the new initiative.² NHPQC also worked to expand upon NNEPQIN's network in New Hampshire to not only include all NH birthing hospitals, but community health and social services, and grassroots organizations as well to ensure participation of those experiencing the worst perinatal care and outcomes. Together, these stakeholders co-created an initial strategic plan with the aim to build a patient-centered, data-driven, evidence-based infrastructure to assure every birthing patient, and infant receives high quality, safe-care.

The NHPQC launched in March 2024 and quickly supported the creation of 11 perinatal coalitions. These multi-stakeholder coalitions address the needs of their communities through local improvement projects and build a care culture that centers and values patient voices and experiences. At a state level, the HRSA State Maternal Health Innovation Grant, award in 2024, funded the creation of the State Maternal Health Task Force (MHTF). The MHTF, with over 50 members statewide, expanded the initial NHPQC Strategic Plan to the current version reflected in this report.

¹Nyamasege CK. 2024 New Hampshire Annual Report on Maternal Mortality. Published online 2024.

²NNEPQIN, housed at Dartmouth Health, is a 20-year-old organization of a network of 50+ birthing hospitals in NH, VT, and ME engaged in disseminating learning best practices.

Snapshot of New Hampshire State Data

State outcomes data demonstrate significant differences across race and ethnicity, education, location, payor and degree of rurality.³ Overall NH ranks well nationally in perinatal health and outcomes, but the data identifies areas for improvement.

Between 2019-2023, the New Hampshire MMRC identified 24 pregnancy-related deaths occurring among pregnant and postpartum women, up to 1-year postpartum. During this time frame, Medicaid covered 71.4% of postpartum deaths, with overdose accounting for 73.3% and suicide for the remainder—all among Medicaid recipients.⁴

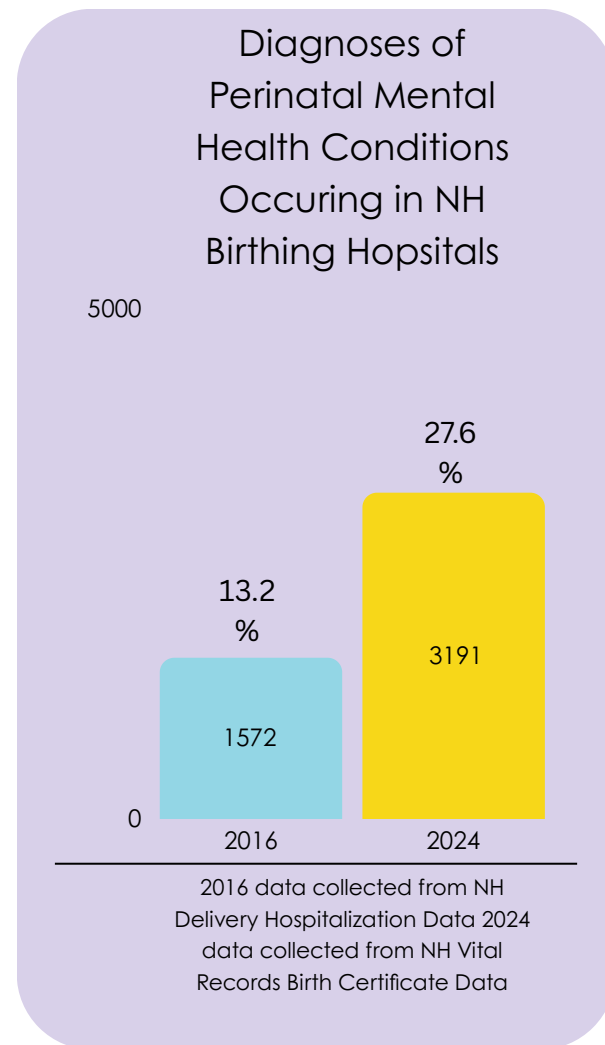
The top contributing factors to these deaths included a history of substance use and treatment, psychiatric hospitalization or treatment, history of childhood trauma, child protective services involvement, and unemployment.⁵

Perinatal Mental Health Conditions (PMHCs)

PMHCs encompass anxiety and depression along with other mental health conditions. PMHCs come through as a priority across all data sources. The prevalence of PMHCs rose significantly in New Hampshire in recent years. Almost one in three women are now diagnosed with a PMHC. Diagnoses of PHMCs rose from 13.2% in 2016 to 27.6% in 2024.⁶

Barriers to Access

Residents encounter multiple barriers to care such as lack of public transportation and broadband access, long distances to care, and limited access to behavioral healthcare. Health systems across the state face challenges in addressing these barriers due to provider shortages and limited behavioral health services.



^{3,4,5}Nyamasege CK. 2024 New Hampshire Annual Report on Maternal Mortality. Published online 2024.
⁶Nyamasege CK. Overview of Maternal Health Characteristics and Outcomes. Presented at: May 1, 2025; Maternal Health Summit

The closure of 11 community hospital OB services since 2000 makes rural communities even further isolated from accessing perinatal health services. The differences in access are also reflected in insurance payor. NH expanded Medicaid in 2014, which decreased the uninsured pregnant population by 43%.⁷ By 2024, 21.1% of resident births were covered by Medicaid or NH CHIP.⁸ However, differences in insurance payor access persist: between 2020-2022, 23.9% of Medicaid recipients and 28.5% of uninsured patients initiated prenatal care after the first trimester, compared to 12.1% of those privately insured.⁹ These gaps contribute to poor outcomes.

The New Hampshire Perinatal Collaborative (NHPQC) formed to create the infrastructure for community driven change and to promote the breaking down of silos to increase communication and collaboration. The foundational patient voice research intentionally worked to engage pregnant and parenting patients in this work and to better understand their lived experiences behind these statistics as a key step toward creating a more patient centered system of care.

⁷New Hampshire Department of Health and Human Services, Maternal & Child Health Division, NNEPQIN, NHPQC. State of Maternal Health New Hampshire.; 2023:62. <https://www.dhhs.nh.gov/sites/g/files/ehbemt476/files/documents2/state-of-maternal-health-nh-feb-2024.pdf>

⁸Nyamasege CK. Overview of Maternal Health Characteristics and Outcomes. Presented at: May 1, 2025; Maternal Health Summit

⁹New Hampshire Department of Health and Human Services, Maternal & Child Health Division, NNEPQIN, NHPQC. State of Maternal Health New Hampshire.; 2023:62. <https://www.dhhs.nh.gov/sites/g/files/ehbemt476/files/documents2/state-of-maternal-health-nh-feb-2024.pdf>

Maternal Health Strategic Plan

In late 2024, the NHPQC received a State Maternal Health Innovation (SMHI) award from HRSA, to support its development and growth. With support from the SMHI award, a Maternal Health Task Force (MHTF) was formed and a more comprehensive strategic plan collaboratively developed to ensure a cohesive statewide approach to perinatal improvements. The MHTF is made up of a broader range of stakeholders that includes statewide leaders, providers, doulas, quality improvement specialists, community health works, and parenting community members.

The MHTF identified four core-drivers to improve outcomes for birthing patients and their families:

- ▶ Sustainable infrastructure that supports ideal birth conditions for everyone.
- ▶ Safe and respectful practice for all.
- ▶ Pregnant and postpartum patients are supported and have the power to make informed decisions.
- ▶ Data and perinatal health outcomes continuously improve.

These core drivers provide the foundation to guide strategies and priority activities for the improvement work. The Maternal Health Task Force and the NHPQC aim to understand what improvements can be made across all levels from upstream policy and infrastructure to community-based care experiences. An examination of the entirety of the birthing landscape in NH, understanding of the impact of labor and delivery closures throughout the state and the varied data supported a strategic plan that addresses both provider and patient needs to “create a culture of caring” and work towards improving perinatal care and outcomes.

Common themes found in the patient voice research were informative to the direction of the Strategic Plan:

- ▶ More access to behavioral health services regardless of payor could alleviate feelings of isolation, shame and stigma
- ▶ Peer-to-peer support resources were a key part of improving communication between DCYF and patients and highlighted the need for continued collaboration to improve utilization of supportive resources.
- ▶ Patients who experienced long distances to care found support in community-based settings, indicating the need for new pathways to develop a multi-disciplinary community-based workforce.
- ▶ Respect for patient choice and their desires were an important driver of their overall experience
- ▶ The fear of the Department of Children Youth and Families (DCYF) significantly impacts engagement in care for our most vulnerable populations.

Patient Centered Collaboration:

Overview of contributing research

The following patient voice research projects will be detailed in this report including the methodology, key findings, specific quotes from participants, and how those findings directly informed the Maternal Health Strategic Plan and coalition activities. Each project section details of the research teams work, and the themes and findings requiring the most urgent attention.

Building Community-Perinatal Quality Collaborative Partnerships to Share Knowledge & Reduce Disparities in Mental Health (PCORI)

Principal Investigators: Daisy Goodman, MPH, DNP, Alka Dev, DrPH and Trinidad Tellez, MD
Funding: the Patient-Centered Outcome Research Institute (PCORI)

NHPQC Emotional Journey Mapping (DCYF EJM)

Principal Investigators: Lisa Lamadriz, MPH, RN, IBCLC, Lauren Chambers, MPH, CPS, Cheri Bryer, CRSW, CLC
Funding: by HRSA SMHI

Snapshot of Access to Maternity Care in Rural New Hampshire: A Photovoice Project (RMOMS)

Principal Investigators: Sanam Roder-DeWan, MD, DrPH, Kailene Jones, MPH, Riley Carbone, Nicole Roeper, Daisy Goodman, MPH, CNM, DNP, Julie Bosak, DrPH, CNM, MSN
Funding: the Dartmouth Institute and RMOMS (HRSA)

Experiences with DCYF as mothers with SUD (DCYF Photovoice)

Principal Investigators: Julie Bosak, DrPH, CNM, Cheri Bryer, CRSW, CLC, Kailene Jones, MPH, Riley Carbone, BA, Sanam Roder-DeWan, MD, DrPH
Funding: HRSA RMOMS

Title V Needs Assessment Surveys & Focus Groups Discussions by New Hampshire Department of Health and Human Services, Division of Public Health, Maternal and Child Health (MCH) Section

Principal Investigators: Laura Suzuki, PhD, MPH, RN-MCH Data Scientist
Co-author: Carolyn Nyamasege, PhD, MPH, MS-MCH Epidemiologist
Funding: Title V Block Grant and State Systems Development Initiative

Themes on Maternal Health Experiences from 2024 & 2025 Pregnancy Risk Assessment Monitoring Survey (PRAMS)

Principal Investigators: Bridget Resse, MPAP,- MCH Data & Block Grant Manager
Co-PI: Carolyn Nyamasege, PhD, MPH, MS,-MCH Epidemiologist
Funding: Title V Block Grant Needs Assessment

Families Flourish Northeast: Experienced-Based Co-Design using Trauma Informed Care (FFNE)

Principal Investigators: Julie Bosak, DrPH, CNM, Cheri Bryer, CRSW, Daisy Goodman, MPH, DNP, Meagan Adams, CLC, CHW, Tamara Barry, Cassidy Flanagan, B.A., Victoria Flanagan, RN, M.S.
Funding: HRSA

Patient Centered Collaboration:

Multiple methods to capture the patient voice

The New Hampshire Maternal Health Strategic Plan is fundamentally grounded in patient voices and lived experiences. We intentionally partnered with different researchers to include multiple methods in order to reflect the breadth and depth of maternal health challenges across different populations and circumstances. Our partners include researchers, community organizations, and state agencies already engaged in this work.

The strategic use of multiple projects also ensured we heard from populations most affected by poor maternal health outcomes:

- **Geographic diversity:**
 - Rural North Country communities (Photovoice), border communities (DCYF EJM in Claremont), and statewide representation (PRAMS, Title V)
- **Experience diversity:**
 - Substance use disorder and recovery (DCYF Photovoice, FFNE, DCYF EJM)
 - High-risk pregnancies and NICU experiences (PRAMS, FFNE)
 - Pregnancy loss and grief (PRAMS, Photovoice)
 - Birth center closures and access barriers (Access Photovoice)
 - Fathers and partners (Title V focus groups)
 - Incarcerated mothers (Title V focus groups)

Beyond these projects, we continue to incorporate the patient voice and experience through research into 2026 with projects that support communities experiencing poorer maternal health outcomes.

How the Patient Voice Shaped the Strategic Plan

Each research project contributed unique insights that directly informed specific elements of the Maternal Health Strategic Plan's four core drivers:

Core Driver	Patient Voice Collaboration
Sustainable infrastructure that supports ideal birth conditions for everyone	PRAMS revealed policy gaps in family leave; Photovoice documented impact of hospital closures; Title V identified childcare and housing barriers.
Safe and respectful practice for all	PCORI EJM emphasized shared decision-making; PRAMS revealed communication breakdowns; DCYF projects highlighted need for trauma-informed care.
Pregnant and postpartum patients are supported and have the power to make informed decisions	PRAMS and Photovoice both emphasized birth autonomy; DCYF EJM identified need for neutral navigators; FFNE showed power of peer support.
Data and perinatal health outcomes continuously improve	All projects provided measurable priorities to track improvements. .

Convergent Evidence:

Themes Across All Projects

Remarkably, despite different methods, populations, and research teams, several themes emerged across nearly every patient voice project:

1. Communication quality determines experience

- Present in: PRAMS, PCORI EJM, DCYF EJM, Photovoice, Title V, FFNE
- Strategic Plan: Strategies to better inform providers with resources and trainings to communication and connecting patients to resources

2. Mental health support is critical and often inadequate

- Present in: PRAMS, PCORI EJM, Photovoice (isolation themes), DCYF projects, FFNE
- Strategic Plan: Emphasizes need for immediate postpartum support

3. Access barriers create dangerous situations

- Present in: PRAMS, Photovoice, Title V, DCYF EJM
- Strategic Plan: Focus on insurance continuity, reimbursement and geographic access

4. Peer support and community connections are protective

- Present in: PCORI EJM, DCYF EJM, DCYF Photovoice, FFNE, Title V
- Strategic Plan Elevating peer recovery workers and community health workers as a workforce priority

5. Economic and social stressors compound health risks

- Present in: PRAMS, Title V, DCYF projects
- Strategic Plan: Informing upstream factors to focus on housing, childcare, and family leave

6. Patients want agency and respect in their care

- Present in: PRAMS, PCORI EJM, Photovoice, FFNE
- Strategic Plan: Central to quality improvement of patient-centered care and informed decision making

7. Fear and stigma prevent care engagement

- Present in: DCYF EJM, DCYF Photovoice, FFNE, PRAMS
- Strategic Plan: Shapes harm reduction and destigmatization priorities

Emotional Journey Mapping

Emotional Journey Mapping is a human-centered approach that visually represents the patient's complete experience in their interactions with a healthcare system including detailing their feelings, motivations, and challenges. Outlined below are two different projects that utilized EJM sessions to map out the experience of patients from 1) low-income, immigrant and LGBT communities and 2) patients with substance use disorder who also interacted with DCYF before and after birth.

Building Community-Perinatal Quality Collaborative Partnerships to Share Knowledge & Reduce Disparities in Mental Health

Project leads: Daisy Goodman, MPH, DNP, Alka Dev, DrPH and Trinidad Tellez, MD

Funded by the Patient-Centered Outcome Research Institute (PCORI)

In 2022, Dartmouth Health in partnership with NNEPQIN, and the Bi-State Primary Care Association, received a grant from the Patient-Centered Outcome Research Institute (PCORI) to develop a sustainable, community-focused infrastructure for disseminating research-based innovations across New Hampshire's birth communities.¹⁰ The researchers utilized two different methods, EJM and Community Engagement Studios (CES) to explore how patient and provider perspectives could inform strategies to improve perinatal mental health throughout the state.

The EJM sessions were structured so participants could share their pregnancy, birth, and postpartum experiences from, including interactions with the health system.

The researchers were able to identify several emerging themes:

- ▶ **Provider compassion and empathy**
- ▶ **Shared decision making**
- ▶ **Mental health and emotional support**
- ▶ **Patient autonomy, empowerment, respect and dignity**
- ▶ **Cultural awareness and respect**
- ▶ **Provider continuity**
- ▶ **Patient education and understanding**
- ▶ **Postpartum and breastfeeding support**

¹⁰At the time of this project's launch, NHPQC was not actively in existence but was in the early planning stages. 49 postpartum women participated in 7 EJM sessions. The participants all had given birth in NH, were invited via WIC text messaging, healthcare offices and community networks. Participant representation included low income, Kinyarwanda-speaking, Spanish-speaking and LGBT communities.

Although designed to elicit information about any experience, participants focused on mental health and postpartum depression experiences arising from perceived neglect and poor treatment during labor and delivery. They discussed interactions with healthcare staff, the importance of personal choice, and culture being respected during the birthing process, as well as past birth traumas.

Following the EJM sessions, participants were invited to join multi-stakeholder CES to co-design solutions to support perinatal mental health across birthing communities in NH, centered on perspectives of patients and other stakeholders, including community representatives, doulas, nurses, physicians, CHWs, social workers, midwives, and lactation consultants. Participants received several prompts to discuss ideas and solutions to shared problems of addressing perinatal health challenges, and methods to disseminate prior research about the solutions that could be potentially relevant in NH.¹¹

The major themes in response to these questions centered around patients' desire to be heard, make their own decisions, be treated as the person in control of their health decisions, and be treated as an equal. The sessions also identified patients' desire to be understood as a person and not just a pregnant patient. To facilitate better connections, participants expressed a need for health systems to have stronger ties in their communities so clinical staff could more easily help patients find services, especially for mental health support.

The researchers identified several potential factors for improving maternal and postpartum outcomes in the state. At a policy level, the expansion of Medicaid to cover 12 months postpartum care is a significant step toward ensuring continuity of care that could facilitate connecting postpartum women to ongoing mental health services.

The major themes centered around patients' desire to be heard, make their own decisions, be treated as the person in control of their health decisions, and be treated as an equal.

¹¹Prompts included the following questions: 1) what makes a provider compassionate and empathetic? 2) How can providers make someone feel like they have more control or say over what happens to them during pregnancy, birth, or postpartum? 3) What can providers do to make patients feel more supported? 4) What are some things healthcare providers and staff can do to help patients when they have anxiety or depression during pregnancy, birth, and postpartum? 5) How can we provide emotional support to patients during pregnancy, birth, and postpartum?

New legislation to reimburse community health workers (CHWs) and doulas has the potential for keeping patients connected to providers and health and social services during the early postpartum period, having a positive impact on mothers at a critical time in postpartum recovery. A re-envisioning of maternity care that emphasizes the community connection reshapes the conversation between the providers and the community facilitated by Doulas and CHWs. This approach not only supports individual patients but also strengthens connections between providers, health systems and the community. Stronger community connections also promote more frequent and meaningful contact between the patient and healthcare systems.

Data to Action:

The lived experiences shared by mothers directly shaped the Maternal Health Task Force's strategic priorities and workgroup structure.

- Promotes action to expand workforce and increase access to doulas and community health workers that respect and understand different cultures, languages and customs.
- Prioritize education on shared decision-making to minimize power dynamics between patients and providers.

NHPQC Emotional Journey Mapping

Funded by: HRSA SMHI

Project Leads: Lisa Lamadriz, MPH, RN, IBCLC. Lauren Chambers, MPH, CPS, Cheri Bryer, CRSW, CLC

Substance Use Disorder (SUD) is the leading cause of maternal deaths in New Hampshire and significantly shapes patient's interaction with the health system and the Department of Children, Youth, and Families (DCYF). The research team utilized Emotional Journey Mapping sessions with participants from Claremont, NH who had cases with DCYF, and had recently given birth. The sessions invited participants to share their experiences from pregnancy through the postpartum period, focusing on interactions with DCYF from the initial report to case resolution.

During these sessions participants spoke about feeling unsupported or not being heard by social workers, providers or other officials from state agencies. Many participants had previous traumatic experiences related to both their past and childbirth. These experiences strongly impacted their levels of stress and anxiety when interacting with DCYF, and contributed to their heightened need for emotional support. Participants also expressed feeling betrayed, lied to, and unsupported by both DCYF agents and in their own communities.

These negative experiences were often intensified by confusion around communication and policies. Participants felt they were being judged as parents before giving birth when DCYF become involved during their pregnancy.¹² Others worried that by entering into a hospital their child would be taken away from them. Participants wanted clearer, more consistent and, reasonable expectations as to DCYF's involvement and what support they would provide to maintain family unification.

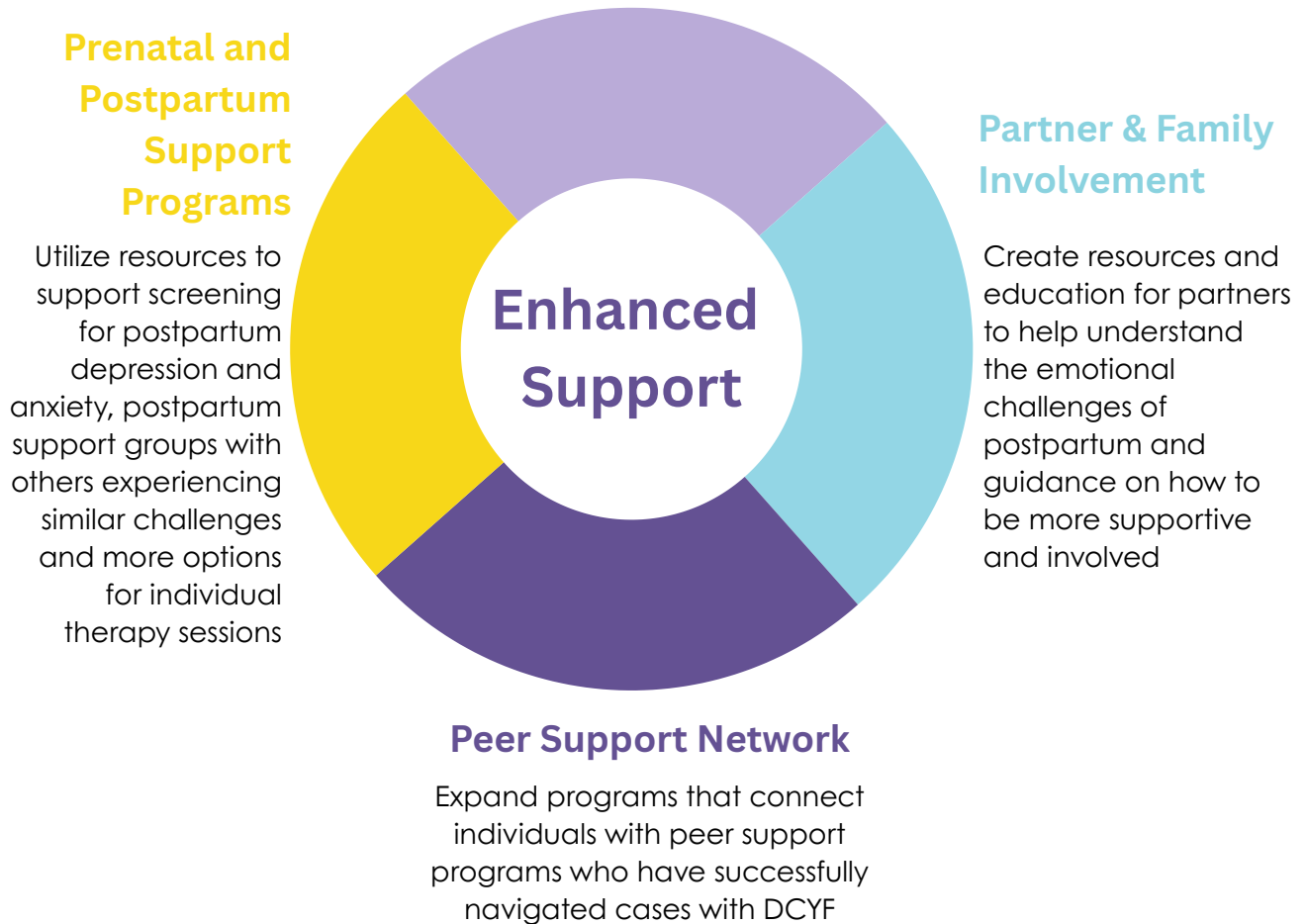
Substance Use Disorder (SUD) is the leading cause of maternal deaths in New Hampshire between 2019-2023.

¹²Claremont, NH is a community along the boarder of Vermont & New Hampshire. State regulations differ in regards to when SUD cases are first reported to DCYF. In Vermont, cases can be opened prenatally, while in NH they are not. Some participants also had experiences with DCYF in the state of Vermont.

Shared-Decision Making & Improved Communication with DCYF

Foster an environment for shared decision making that communicates the goals and expectations of DCYF and ensures that patients understand the process. Clearly and frequently explain the rationale of the intervention, the anticipated outcomes and if possible, available alternatives.

Support from a neutral Peer Navigator to assist with completing the requirements that DCYF lays out for families.



In contrast, participants with access to community support systems that included mental health and well-being check-ins, felt more successful in meeting the expectations set by DCYF. These types of community resources fostered an environment of openness, reduced stigma for seeking help, and support experiences that could otherwise feel isolating or shameful. These community support systems were integral for families to not only manage challenging and difficult circumstances but also celebrate milestones that contributed to their overall success. These supports underscored the importance of expanding resources that empower families.

Participants identified several key recommendations that highlight the need for early, clear communication and shared-decision making during prenatal and postpartum care. These recommendations also empowered patients to play an active role in determining their Family Care Plans and discharge from the birthing hospital.

The EJM sessions revealed the disconnect many patients feel from a system designed to support them. Findings highlight gaps in mental health resources and communication, pointing to opportunities for stronger perinatal collaboration. Participants of these EJM sessions also clearly defined the idea of having a neutral peer navigator to assist with completing the DCYF requirements laid out for families. This type of actionable feedback stresses the need to have patient-voices at the table and to work collaboratively with DCYF on shaping improvements.

Data to Action

In addition to informing the strategic plan, this patient voice work created an opportunity to collaborate with DCYF in NH. DCYF leadership and staff are collaborating with the NHPQC community coalition in Claremont to co-create improvements working toward the mutual goal of supportive experiences when DCYF involvement is necessary.

Photovoice

Photovoice is a participatory research method that enables participants to record and reflect on a topic area through photography and narrative storytelling. A method developed by Caroline Wang and Mar Ann Burris, photovoice aims to capture the perspective of an individual's lived experience, reflect on this experience with images and words and to advocate for improvement through the exhibition and dissemination of photos.¹³ It is a tool to promote and foster critical dialogue and knowledge about a community's issues in both large and small groups discussions and it gives policy makers a visual representation of a community's challenges. Below, we discuss two projects that utilized Photovoice to capture the patient-voice.

► Findings

The burden of poor access is shifting from the health system to rural families

► Themes

People make compromises & find creative solutions

There is a mismatch between needs & available services

People feel unheard & self advocate for quality care

People feel isolated, especially in the postpartum period & after pregnancy Loss

People are thriving in motherhood & building resilience

Access to Maternity Care in New Hampshire: A Photovoice Project

Project leads: Sanam Roder-DeWan, MD, DrPH, Kailene Jones, MPH, Riley Carbone, BA, Nicole Roeper, Daisy Goodman, MPH, CNM, DNP, Julie Bosak, DrPH, CNM, MSN

Funded by: Funded by the Health Equity Research Pathways Program and NH RMOMS (HRSA)

As described in the background, over a 20-year period, 11 of the 26 birthing units closed resulting in a care gap in the rural regions of NH. These closures have significantly impacted rural resident's access and choice in care. This Photovoice project sought to understand the experience of living in rural areas that have lost access to maternity care in NH. The study team is composed of Dartmouth Health, Dartmouth College and Women of the Mountains Birth Initiative members. It was jointly funded by The Dartmouth Institute and RMOMS. Seventeen people who were either residents or accessing care in the North country of NH were recruited for the study.

¹³Wang, C., & Burris, M. A. (1997). Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment. *Health Education & Behavior*, 24(3), 369–387. <http://www.jstor.org/stable/45056507>

The project comprised of three cohorts – two based in Gorham, NH and Littleton, NH, both in person, and one virtual group from Colebrook, NH. Participants were either currently pregnant or had been in the last 5 years and had experienced poor access to maternity care.

In the first session, participants learned photography techniques from the World Story Exchange, a community-based organization in Vermont. Over the course of the next 3 sessions, in their individual cohorts, participants co-created prompts and analyzed common themes in their stories through their photographs. During a final session, the different cohorts came together to conduct a participatory thematic analysis of their photos, to share stories with one another and to organize a public exhibition of their findings. Through this process, participants generated key insights into their experiences.

In May 2025, participants attended the NH Maternal Health Summit to present their photos and share their experiences with stakeholders from the community and local health systems. Participants described both the physical and mental barriers to care and how these experiences impacted their ability to have a positive birth experience. Through their photographs, participants demonstrated the vastness of rural geography and talked about feelings of isolation and loneliness. Participants also described creativity, resilience, and pride and identified areas for improvement (Table 2).



Table 2. Where Systematic Improvements Are Needed

Communication	Resources and Access	Provider Education
Provider-provider, provider-patient, provider-community resources	Sharing of community resources	Smooth referral between clinical and social service providers
Benefits cliff: “not qualified” but still need help	Coordination scheduling for a mother-baby visit or access to family medicine	Stigma of accessing of resources
Isolation of people with SUD	Increase access and integration with pregnancy groups and resources	Shared decision-making and harm reduction Focus on strengths rather than risk
Language around Advanced Maternal Age (geriatric pregnancy)	Support and implementation of a variety of ways to access resources for rural families like telehealth visits and zoom sessions	Anesthesiology Regulations pertaining to C-Section/VBAC options

Overall, the participants identified 5 key takeaways – and the challenges and strengths associated with them.

► **Make compromises and find creative solutions while making decisions about maternity care by balancing quality and access**



Misty Shroud: It was very hard to see on this early morning to get my glucose test. I had to pack my whole family in the car, barely awake, to make it to the hospital which is 50 minutes away. Although, they become more accustomed to these day trips to my AMA (36) requiring more frequent visits. – Brianna Lareau

Stay with the In-Laws: Because my husband and I lived a good 45 minutes from the hospital, my FIL and his girlfriend kindly offered to let us stay at their home with them, a short 5 minutes to LRH. This was a great option for us; however, we did have to uproot our lives to go and stay with them for a little bit to ensure we would make it to the hospital safely and within a short amount of time. - Maylynda Emerson



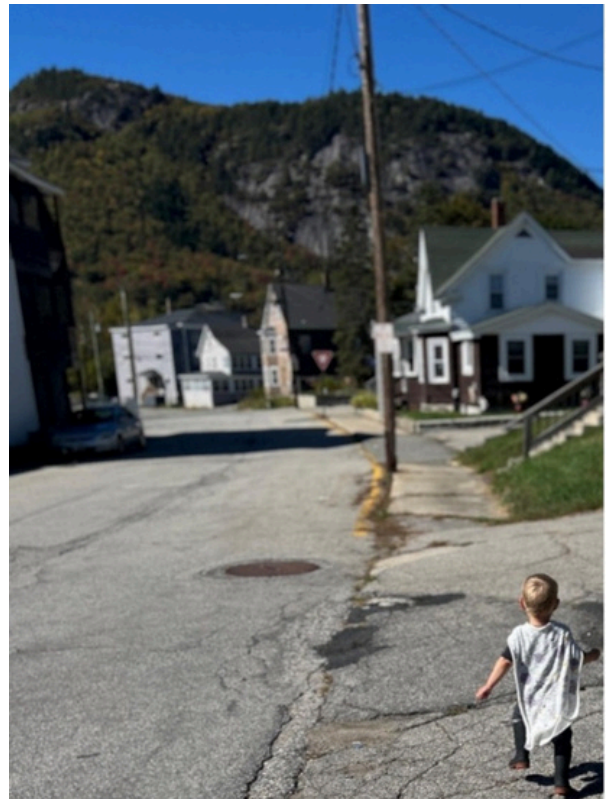
► **Experience a mismatch between needs/preferences and services available**



Obstruction of choice: To find support of choice in birth after cesarean, I had to de-rail, go off of the tracks of the usual course and leave North Country. The path to avoid a planned cesarean was time consuming, expensive and stressful. -Anonymous

► **Feel unheard and actively advocate for their preferred maternity care**

*It's like I have to be superwoman in a world I know nothing about.
-Cassandra Mercer*

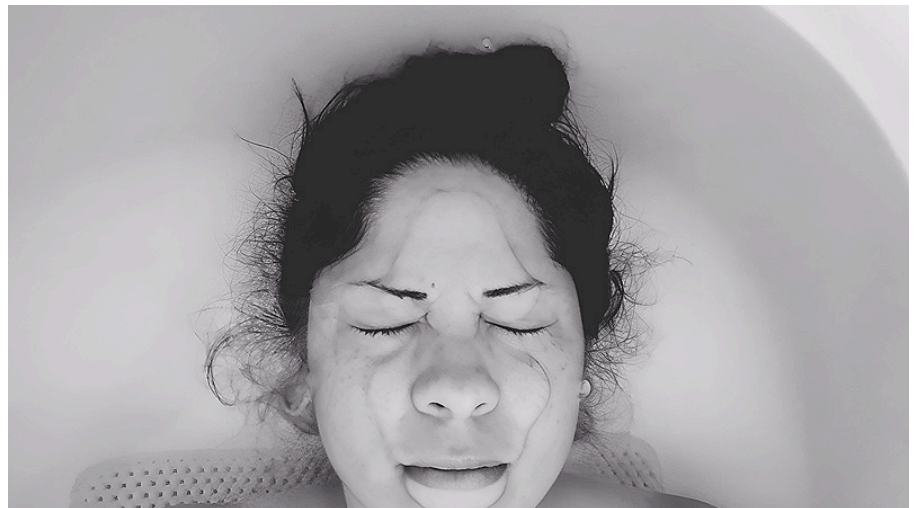




Self: Leaning into the support of research and confidence in my body as professional support was unavailable to me in the North Country. -Anonymous

► Experience isolation especially in the postpartum period and during pregnancy loss.

Exhausted and Overwhelmed: A mother in the North Country struggles to find solace in the midst of prenatal and postnatal care challenges. The isolation and lack of access to resources weigh heavily on her, leaving her feeling drained and helpless... -Rose Toner



Through the storm of grief and loss and through the process of having our rainbow baby, we were seen and reassured with love and support in honoring our daughter's memory and ensuring our son made it safely. - Jessie Ingerson

▶ **Thriving in motherhood and building resilience even in the face of challenges.**

*There is always a light on at the end of the darkness.
-Brittany Leighton*



In describing the key takeaways, the participants also were able to highlight community strengths that could be expanded. Participants identified these strengths as sources that could help bridge the gap in access and help patients make better informed decisions about care.

- ▶ Support groups – prenatal, postpartum or pregnancy loss
- ▶ Group visits – prenatal and postpartum
- ▶ Accessing Doula and Community Health Worker programs
- ▶ In-home prenatal and postpartum visits
- ▶ Breastfeeding support
- ▶ Supportive shared decision-making on elective induction for geographic risk
- ▶ Early-head start
- ▶ Pregnancy loss support by providers

To improve overall access and quality of care, participants identified three major categories where gaps exist and areas for specific improvements. These categories reflect the themes present in the individual participant research and identify where systematic improvements are still needed.

The Ripple Effect of Work

North Country Photovoice Project, 2024-2026

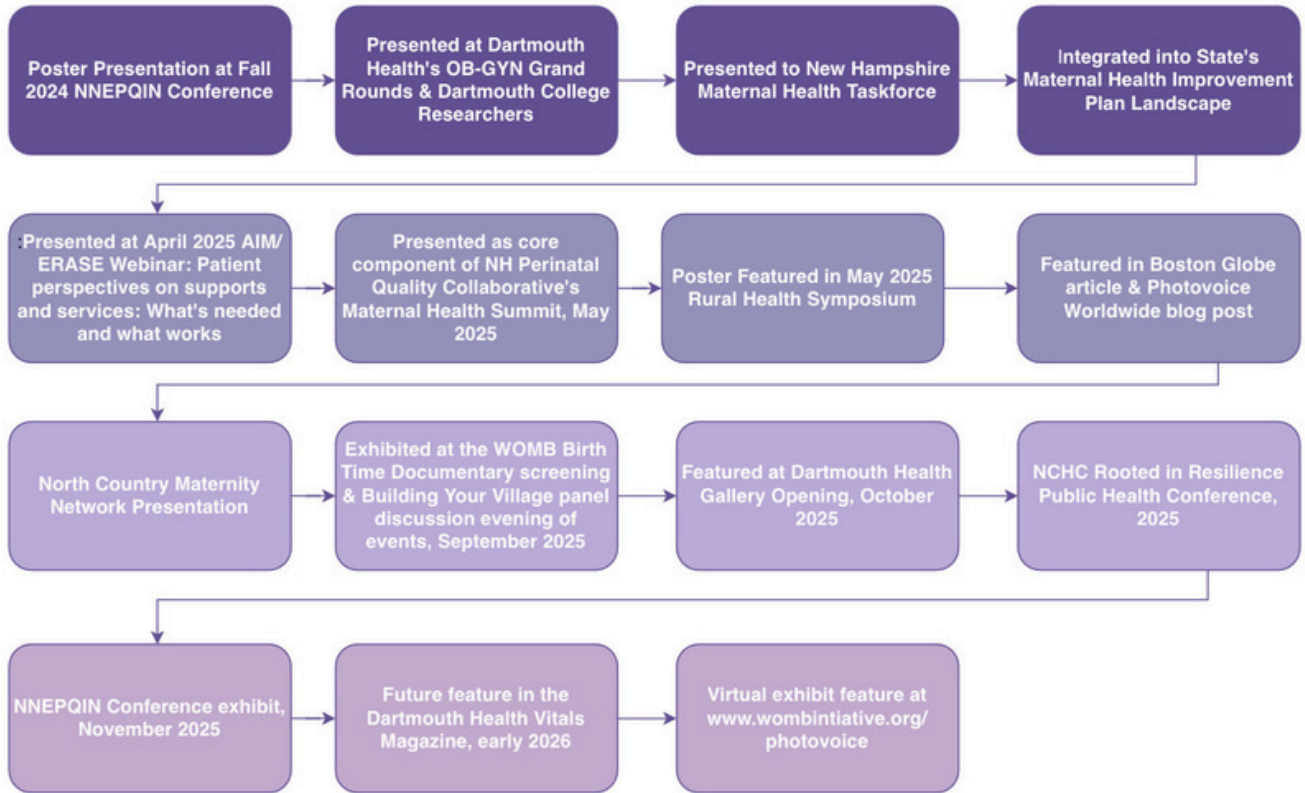


Table 3. Opportunities for sharing the Snapshots of Maternity Care in Rural NH

The ripple effect of the participants work has also been seen across New England demonstrating the power of the participants' voices as a driver in conversations around access to maternity care in rural areas.

Experience with DCYF as Mothers with SUD

Funded by: Funded by NHPQC

Project leads: Julie Bosak, DrPH, CNM, Cheri Bryer, CRSW, CLC, Kailene Jones, MPH, Riley Carbone, BA, Sanam Roder-DeWan, MD, DrPH

To capture the voices of moms and their experiences and interactions with Department of Children, Youth and Families (DCYF), a separate photovoice project was supported and implemented in partnership with RMOMS, SMHI and community engagement manager from WOMB. We know from the data that substance use disorder (SUD) is the leading cause of maternal deaths in New Hampshire. To understand the role that active substance use plays in pregnant or parenting women's ability to access care, we invited participants with SUD to a specific photovoice project to understand their experience with the NH Department of Children, Youth and Families (DCYF).

The goal of this photovoice project was to understand the participants barriers to accessing care, how their interaction with DCYF affected their decisions around care-access and give a voice to these stories to inform improvements. The group comprised of 3 women who were either from NH or accessing care in NH, pregnant or had been in the last 5 years, struggled with SUD and experienced DCYF engagement.

During the sessions, participants talked about how their fear of DCYF made them less likely to seek-out prenatal care. The fear of losing their child or children, actively using or a combination of both were significant factors for avoidance. One woman reported not seeking out any prenatal care until the birth of her child and that she was actively using until the day before. These stories highlighted that the shame, fear and stigma of substance use disorder can cause patients to withdraw from the health system.

Participants who did engage with DCYF found that it was often challenging and discouraging. Participants reported feeling frustrated by the lack of support and acknowledgement of the steps they had taken to ensure they could be united or reunited with their children. There were also significant feelings of despair for those who were unable to be united – one noted that she fell out of recovery after a disappointing day in

► Themes

Avoidance of Prenatal care due to fear

Looking for both guidance and emotional support

Reevaluate Policies to improve outcomes

Sustaining support to reunite families

Review time frames for parent rights & addiction

court. While all the participants recognized the need for DCYF's involvement, they had hoped for more supportive interactions.

Despite these challenges, participants also identified successful interventions. Those who had been able to implement the Family Care Plan with their provider during their prenatal period, reported better outcomes and were able to stay together with their child. They also expressed that having an action plan made them accountable and gave them a tool to stay on track. Those with an action plan were more likely to attend prenatal visits regularly and receive behavioral health support while they were struggling. The Family Care Plan also provided a structure that supported their ability to maintain custody.¹⁴

Through their photographs and narratives, participants revealed several key findings about their experiences:

▶ **Women avoid prenatal care due to fears of child removal negatively impacting health outcomes and their chances of successfully maintaining custody**

In the first six months of my pregnancy, I didn't get any prenatal care due to my active addiction and my fear of what they (doctors and DCYF) would think.



¹⁴A Family Care Plan is a document that outlines care strategies, supports and services for parents with substance use disorder. This plan is developed collaboratively with patients and their support team.

- ▶ **Recognize the need for DCYF involvement at times, but still want to be shown kindness and belief in their ability to mother.**

Born to my active addiction, I lost many years of it to grief or darkness or a wound that wouldn't close. I was pregnant and too scared to get help because of the fear I had of DCYF taking my baby. Which in the end my fear happened. DCYF focused so much on what I did wrong in my pregnancy instead of helping me get better or be reunited with my son.

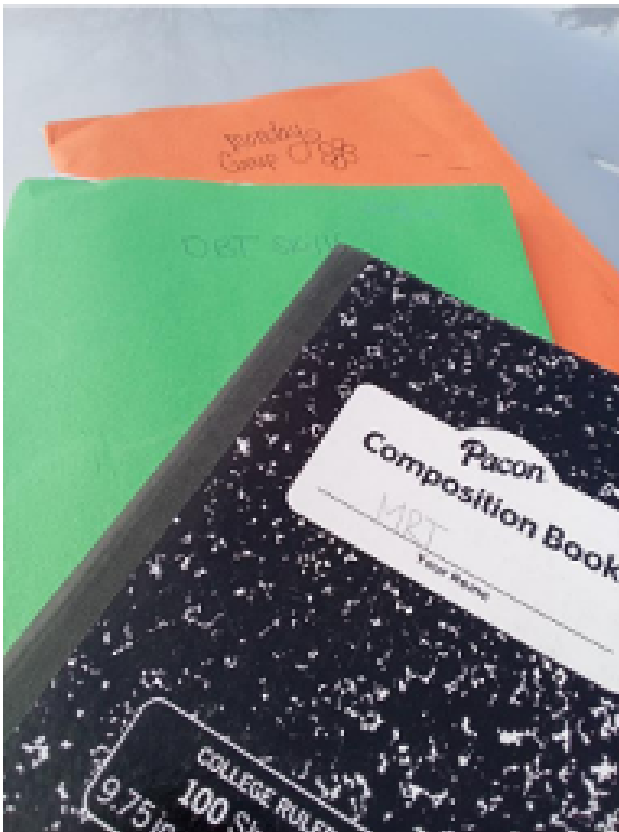


- ▶ **Longer term policy changes that would be more supportive and increase likelihood of success.**



Happy baby boy at home where he belongs. Thankful for DCYF seeing the good in me and allowing me to dive right into motherhood and form an unbreakable bond (no period of separation).

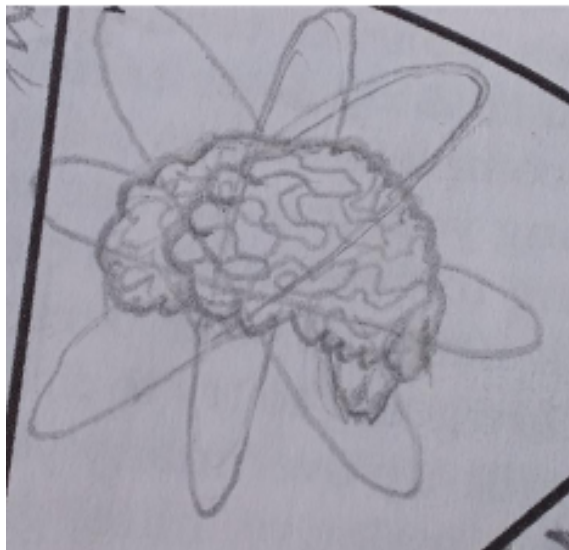
I worked very hard trying to fight to get my children back and DCYF did not give me any support. They just kept scaring me telling me the foster parents were fighting to keep my daughter, no matter what I did right. It shouldn't have been like that. I should have had another chance. I was in treatment at Dartmouth, got income, my own place, sober, and they still never gave me a chance ever again.



The heart to give me a chance to change through groups and programming They helped me connect with the resource I need to take care of myself and become the person I need to be.

► **Longer term policy changes that would be more supportive and increase likelihood of success.**

After losing my children from hospital, I went home to [an] empty house. After losing my children, I can't even describe the pain and all the emotion I felt. It's the worst thing a mother could ever go through, especially when I really was not a bad mom. I loved my children; I just struggled with addiction for a little bit. I needed more support from others. It made my addiction worse after I lost my children, but then after a couple months I got up and fought hard, got sober, and that still wasn't enough for DCYF.



Even though it was tough emotionally, the tough choice was the right choice and I needed that push to begin on the right path. It was hard in the beginning, but it was the best possible path for my son's long-term happiness.

▶ **Lengthen time frame for final parental rights decision in cases of addiction.**

I ended up getting my own apartment after I lost my children for my children. I was sober and [DCYF] still had nothing nice to say. They were still fighting to keep my babies from me, said it was too late which was wrong. I had visits every week with them. No matter what I did right, [DCYF] never wanted to give me a chance to be the mother they deserved.



Building on these themes, future groups will be centered around the perspectives of women with SUD to consider strategies and actions to reduce the avoidance of prenatal care, build a support system with DCYF and include more community-based organizations to keep families united and together.

Data to Action

- The Maternal Health Task Force's strategic plan prioritizes increasing postpartum support groups to address isolation, accommodations during transitions, and holistic care that supports their complete well-being.
- For mothers in recovery, in addition to postpartum support, a supportive workforce of peer recovery workers and community resources are prioritized to keep families together whenever possible.
- This patient voice work informed the strategic priorities and created an opportunity to collaborate with DCYF in NH to realize these. DCYF leadership and staff are collaborating with the NHPQC community coalition in Claremont to co-create improvements working toward the mutual goal of supportive experiences when DCYF involvement is necessary.

Focus Groups, Surveys and Interviews

Title V Needs Assessment Surveys & Focus Groups Discussions by New Hampshire Department of Health and Human Services, Division of Public Health, Maternal and Child Health (MCH) Section

Principal Investigator: Laura Suzuki, PhD, MPH, RN-MCH Data
Scientist

Co-author: Carolyn Nyamasege, PhD, MPH, MS-MCH
Epidemiologist

Funding: Title V Block Grant and State Systems Development
Initiative

The New Hampshire Title V Program, funded by the Health Resources and Services Administration (HRSA) through the Title V Maternal and Child Health Block Grant and the State Systems Development Initiative (SSDI) Grant, conducts a statewide needs assessment every five years to identify the most pressing issues facing the maternal and child health (MCH) population. This assessment evaluates the challenges, needs, strengths, and assets across all population domains: pregnant women, infants, children, children with special health care needs (CSHCN), and adolescents, with the goal of improving health outcomes and strengthening both state and community partnerships. As part of the 2026-2031 needs assessment, the New Hampshire Department of Health and Human Services, Division of Public Health, MCH section, conducted research from October 2024 through February 2025 using survey, landscape analysis and focus group discussions (FGDs) to collect data regarding all the population domains listed above. The findings informed the selection of priority areas within each domain, guiding the MCH program's strategic focus for the next five years to advance maternal and child health outcomes and strengthen partnerships at the state and community levels.

Surveys

The statewide survey was distributed via survey monkey with a total of 270 responses and covered topics ranging from maternal health through adolescent health. For the purpose of this report, we will only review the maternal and infant health responses.

Both sections outlined 15 issues and asked respondents, based on their personal or professional experience, to indicate their level of concern about that specific issue. (See appendix for full list of survey questions.)

For maternal health issues, respondents had a big concern around topics such as depression and anxiety, support postpartum and access to prenatal care. Respondents commented about insurance access, difficulty in tracking resources and sharing them with families, substance use disorder, and policies that were more supportive to working parents in order to have sufficient time to recover and bond with their newborn.

Table 4. Survey of Top Maternal Health Concerns by Priority Level

<p>Top 5 Issues “A very big concern”</p>	<p>Top 5 Issues “Somewhat of a concern”</p>	<p>Comments</p>
<ul style="list-style-type: none"> ▶ Depression and anxiety ▶ Access to support after having a baby ▶ Substance use ▶ Inadequate insurance ▶ Access to prenatal care 	<ul style="list-style-type: none"> ▶ Intimate partner violence ▶ Breastfeeding ▶ Emotional and economic abuse ▶ Substance use ▶ Inadequate insurance 	<p><i>“...resources are still scattered and there isn't a good system to keep track of those resources to share with patients and families.”</i></p> <p><i>“Substance use is a huge issue for all populations in NH.”</i></p>

In the infant health section, respondents expressed concerns around parental substance use, parental mental health, infant substance exposure, and access to healthcare and developmental evaluation. Several comments also identified a need for more postpartum support for mothers, mental health checks and postpartum depression. Comments also expressed concern that many providers do not take Medicare/Medicaid and that private insurance had high deductibles with a lot of out-of-pocket costs.

Table 5. Survey of Top Infant Health Concerns

<p>Top 5 Issues "A very big concern"</p>	<p>Top 5 Issues "Somewhat of a concern"</p>	<p>Comments</p>
<ul style="list-style-type: none"> ▶ Parental substance use ▶ Parental mental health ▶ Exposure to substances in utero ▶ Access to healthcare ▶ Access to developmental evaluations 	<ul style="list-style-type: none"> ▶ Born premature ▶ Low birthweight ▶ Abuse and neglect ▶ Screening for development ▶ Exposure to secondhand smoke 	<p><i>"Not enough providers that take Medicare"</i></p> <p><i>"more appointments for moms after she delivers baby to check in on her mental health and wellbeing"</i></p> <p><i>"access to nutritious, affordable food, particularly those in food deserts."</i></p>

It is important to note that while the survey had a low response rate (270 total responses), the responses are supportive of the other patient voice work we have discussed so far in this report.

Focus Groups¹⁵

To hear directly from communities and seek voices that were unlikely to be heard through the online survey and to validate the survey results, NH DHHS MCH section organized 7 different focus groups made up of 2-7 people. The groups included Community Health Workers, Fathers, Latina Moms, African Immigrant moms, moms, incarcerated moms with a child under the age of 1.

Participants discussed the need for better connection to resources and helping to support moms and parents during what could be a very socially isolation time.

¹⁵This is a preliminary analysis of the data that was completed with computer generated themes and reviewed by project team.

“So I think that a lot, for single moms, especially first time single moms, to have someone come in for an hour of relief, would be helpful. When I had my 3rd baby, because of background, someone at [Hospital X] gave me a lot of time and resources. Even with the help that I had, I wouldn’t have made it even being on maternity leave, I wouldn’t have made it without this lady who helped me.”

The groups identified resources that could be beneficial to families, including nurse visits at home, support groups for moms and dads, and education around parenting and coparenting in high conflict relationships.

“One thing I found significantly beneficial that I don’t know if others in my community access had too- I’m not sure if it’s because I gave birth at a larger hospital or not, but I was offered a home health nurse to come to the house. I found that so helpful. Just coming home from the hospital and having that extra support was incredibly helpful for me- just to hear someone say, “he’s gaining weight, he’s responding well.” These services were available in about 3 days- I saw them before the pediatrician.”

“Mental health programs targeted to men – something that understands what fathers are up against. Father is primary income earner.”

The participants also looked to state and local organizations such as DCYF and WIC (Women Infants and Children) to be more proactive in supporting families. Families expressed a need for solutions around affordable housing options, maintaining their insurance, and accessing transportation and nutritious food.

“Why can’t women get more FS (food stamps) during pregnancy- they get the same amount as someone who isn’t pregnant. I think those kind of things would be helpful for women. Underlying issues in pregnancy really flare up during pregnancy!”

“I think that for a lot of NH moms, there wasn’t that nurse or doctor, that gave me the resources to have a healthy pregnancy to help me with my addiction. Either get off the drugs or I had to keep using the drugs. DCYF don’t help for nothing. For an industry that strides for kids to be with their parents, they should provide the resources for that to happen. I also feel that there are underlying health issues- a lot of them can happen during pregnancy- I wish I had more help for those factors during pregnancy.”

Dads especially noted that it was difficult for them to support their partner or children with access to WIC or medical records since they are often left out of these systems.

“Better recognition of the role of fathers – married or not, traditional family or on their own, changing departmental names to reflect that relationship/role greater commitment to the role of fathers in parenting.”

Central to the themes of the focus groups was the need for increased and better communication in order to provide resources, support parents and identify gaps in access and needs. One participant identified the disconnect between their experience between visits with the OB GYN and primary care provider and the need for better communication between providers and how different feeding options were presented postpartum.

“I found a lot of info through OB but then they would kick me back to primary care and then OB. I thought I was caught in between and juggled with OB and primary care. I had more anxiety during pregnancy than I normally had. I was also thinking about prior to giving birth I had done a lot of research on how to plan and feed my baby- I felt a significant amount of pressure that breast feeding was my only option, so after I had my son, I was very torn with supplementing with formula. There could have been a better approach that their other methods of feeding your child.”

Another participant expressed the difficulty in knowing what resources were available at the appropriate time.

“I wasn’t aware of the resources until my son was over 1 year old and then I started panicking. I think there are still some resources that I don’t know about and I’m still spending time learning what’s available in my community.”

Themes of access to resources and providers, perinatal mental health conditions, community support and substance use are concerns patients have expressed throughout the different patient voice work. These themes support what is integrated into the strategic plan priorities of the NHPQC.

Data to Action

Perinatal care in the community that supports families and addresses information gaps, improved resource networks and addressing the needs that families share are priorities in the strategic plan.

Themes on Maternal Health Experiences from 2024 & 2025 Pregnancy Risk Assessment Monitoring Survey (PRAMS)

Principal Investigators: Bridget Resse, MPAP,- MCH Data & Block Grant Manager

Co-PI: Carolyn Nyamasege, PhD, MPH, MS,-MCH Epidemiologist

Funding: Pregnancy Risk Assessment Monitoring System

The final open-ended question in the Pregnancy Risk Assessment Monitoring System (PRAMS) survey questionnaire invites mothers to share their personal experiences during pregnancy and the postpartum period. The question asks: “We would love to hear more about your story! Is there anything else you would like to share with us about your experiences around the time of your pregnancy? Please use this space to tell us.”

Thematic analysis of these maternal health responses reveals that women’s experiences during pregnancy, birth, and the postpartum period were influenced by a combination of clinical risk, provider communication, mental health support, access to care, and other factors, as described below.

► Quality of Care & Communication

Respondents identified both positive and negative provider communication as an important element of their perceived quality of care. Responses revealed a clear divide between experiences marked by poor communication and those characterized by clear, compassionate, and patient-centered care.

Communication Breakdowns & Dismissals

Negative communication experiences included feeling dismissed, unheard, or inadequately informed, sometimes contributing to delayed diagnoses or worsening outcomes:

PRAMS responses centered on the following themes:

- Quality of Care & Communication
- High Risk Pregnancy & Medical Complications
- NICU & Prematurity
- Mental Health & Emotional Well-Being
- Access to Care & Coverage
- Provider continuity
- Birth Autonomy & Preferences
- Loss, Trauma and Grief
- Fertility & IVF
- Paid Family Medical Leave
- Social & Economic Stressors

¹⁰As part of ongoing Title V Block grant needs assessment activities, the PRAMS Data & Decision Support team reviewed write-in responses from the 2024 and 2025 survey booklets. The objective of this analysis was to identify emergent topics not explicitly captured in structured survey items and to further examine issues elaborated upon by respondents. Write-in responses were compiled in Excel and subjected to systematic qualitative review. Following review, the MCH Epidemiologist and the MCH Data and Block Grant Manager identified ten analytic themes. Responses were coded to one or more themes, and Excel pivot tables were used to quantify and rank themes by frequency from most to least prevalent. Finally, a narrative summary of the key themes, including illustrative quotes was developed.

"...because of their neglect and non-willingness to listen to me when I told them I was sick, I developed HELLP syndrome, kidney failure, liver failure and my son and I only had a small chance of survival. Thankfully, he is healthy now, but it has completely changed who I am today...."

Others described a lack of transparency during hospital stays, which heightened anxiety and confusion:

"...did not explain to us why we were staying 2 extra nights, the last day at the hospital they finally explained it was jaundice. But nobody cared to explain why we were being kept there when I had a very good all-natural labor"

In some cases, respondents perceived providers as rushed or overly directive, using coercion to influence patients' decision making such as offering medications or recommending interventions like vaccines without adequate discussion of risks or alternatives. They described perceived pressure from healthcare providers to accept their treatment plan despite informed refusal.

"They just offered medications as if they were the safest thing in the world for babies and did not mention side effects...."

"There were times when shots were pushed on me, despite my fully informed decision, refusing to accept my declinations, with the lack of safety in the DTap specifically. To expose an unborn child, that cannot consent to receiving any shots to the level of toxins present is immoral, unethical, and evil..."

"I had a VBAC and a very healthy baby 2 months ago. This was only possible because I switched from one provider who did not support VBACs to a new provider and hospital at 30 weeks who did support me having a VBAC. I was so happy with my birth experience but was disappointed with the fear tactics that my prior OB used to convince me to schedule a repeat csection. Our csection rates are far too high and I fear that many women don't have supportive providers. I also had a doula during this pregnancy which made such a huge difference. It's something that I hope insurance companies will cover in the future"

Clear, Compassionate & Patient-Centered Communication

In contrast, positive communication and collaborative decision-making were described as calming, stabilizing, and protective, especially during medically complex pregnancies.

Others highlighted how transparency and coordinated care reduced their burden during stressful moments. Positive communication was also described as rooted in provider's experience, trust, and respect for patient concerns:

"I am grateful for the care I was given both by my midwife at x hospital and by all the staff at x hospital. Everyone was in agreement that my preeclampsia would only get worse but were able to keep my mental state somewhat calm and allow me to avoid a c section. I am forever grateful for my providers that they were able to make clear judgements based on their years of experience and nothing else"."

These findings indicate that communication quality plays a critical role in patient safety, trust, and overall maternal experience.

► High-Risk Pregnancy & Medical Complications

Nearly one-third of respondents reported high-risk pregnancies involving conditions such as preeclampsia, HELLP syndrome, gestational diabetes, placental abnormalities, and fetal growth restriction. Many experienced frequent monitoring, early induction, or emergency cesarean delivery. Several respondents described rapidly escalating conditions:

"I had preeclampsia leading to a failed induction and emergency c section. I then hemorrhaged all night and had a rapid response due to my loss of consciousness. My baby was born 5 weeks early but didn't need the NICU. I lived, and I was able to breastfeed immediately. I am blessed."

Others emphasized the physical and emotional toll of prolonged high-risk management. These narratives highlight the importance of timely diagnosis and coordinated specialty care, when managing medical risk.

"I had some anxiety and guilt about needing to take this medicine so that I could be healthy when there was a chance it could affect my baby, even though I knew my first child had been fine when I took it during pregnancy"

► **NICU & Prematurity**

Some respondents described experiences with prematurity and NICU admission. Parents frequently reported long hospital stays, separation from their infants, and ongoing uncertainty about health outcomes.

"My son has been in the NICU for over 80 days... it has taken a toll on my mental health."

While many respondents expressed gratitude for NICU clinical care, emotional and psychological support for parents was often described as insufficient or delayed:

"There was very little to no support service provided to mothers to help deal with this emotionally."

These experiences suggest a need for more structured parental support alongside neonatal medical care.

► **Mental Health & Emotional Well-Being**

Mental health concerns were widespread and often closely linked to medical complications, traumatic births, and NICU experiences. Respondents described anxiety, depression, postpartum mood disorders, and long-term emotional impacts.

"After birth my daughter had to be transferred to the NICU unexpectedly. There was very little to no support service provided to mothers in the hospital to help deal with this emotionally. Although counseling contacts are provided it is often overwhelming and wish there was an opportunity to speak with someone more quickly when dealing with postpartum symptoms."

"I got to 10cm dilated but when my water was broken my baby fell and landed on his umbilical cord and it was wrapped around his neck. This then made his heart rate drop and mine increase. I was sent for c-section. My baby was born at 4lbs 3 oz. He was then sent to NICU. He was in NICU till the following Monday while I was sent home on Sunday. I did have the baby blues postpartum, but my Zoloft helped greatly."

Many respondents emphasized that mental health needs should be addressed immediately post-partum rather than at the standard six-week visit:

"The first one to two weeks is really hard."

When screening and treatment were timely, respondents reported meaningful benefits:

"Ob's office did a great job screening for mental health both during and after. I had PPD and they put me on SSRI that was very helpful."

These findings underscore the importance of early and integrated perinatal mental health care.

Access to Care & Coverage

Access to care, including insurance coverage, provider availability, and access to specialty services, strongly influenced maternal experiences. Some respondents reported delayed diagnoses or limited prenatal care due to insurance gaps or cost barriers:

"Due to lack of insurance I didn't know I was having twins until 30 hours prior to delivery. Only reason why I knew was I had UTI symptoms. I was going to have a home delivery so I didn't go in, I would have had a twin home delivery alone and scared because x determines me making what I made was too much for 3 people and private insurance was too expensive for out of pocket cost."

Others described needing to travel out of state mainly Massachusetts for appropriate care:

"New Hampshire didn't have the specialists or level of care needed."

In contrast, respondents with continuous Medicaid coverage and nurse outreach described these services as stabilizing and supportive:

"The nurse called me every month and helped me access services."

These accounts highlight the protective role of insurance continuity and care coordination, particularly for high-risk pregnancies.

► Birth Autonomy & Preferences

Birth Autonomy & Preferences included reported feelings of pressure, hesitation, medical skepticism, and preference for alternative care approaches. Other preferences among respondents described lifestyle behaviors before, during, and after pregnancy (cannabis or herbs use, dietary habits, and holistic practices such as acupuncture). Reported need for self-advocacy often corresponded with a negative experience related to medicated versus un-medicated births as well as birth delivery method (vaginal or c-section). Preferences associated with positive experiences often cited the decision to work with a midwife or doula and location of birth (i.e. hospital, home birth, birthing center).

"I believe that living a healthy lifestyle includes things like fresh air, clean water, exercise and sunshine. My family and I regularly see a chiropractor for healthcare maintenance. We no longer routinely visit a primary care practitioner/pediatrician. There is no such thing as a 'well child check'. It's a scam to get your children into the doctor to vaccinate them, which we refrain from. My last 2 babies were born at home, and this last baby was an unassisted homebirth. We don't eat fast food. We cook 99% of our meals. We don't drink alcohol or use tobacco products. We limit TV and screen time and prioritize playing outside with our children. The medical system is corrupt and needs an overhaul."

"I use an outpatient birth center and had an excellent experience. I think that if midwife outpatient births for healthy moms (that were) low risk pregnancies were made more common it would help reduce hospital burdens for the high-risk moms who really need that level of care. I love midwives and at a state level I'd love to see them face less regulatory challenges and barriers as providers."

"We had a home birth with a midwife and it was the best experience I could've ever asked for. It required a lot more education and preparation than I was offered/sought out during my first pregnancy but I truly believe pregnancy and birth would be safer for all if more providers respected natural birth and took a low intervention, low physiologic approach to giving care."

These accounts suggest self-advocacy and autonomy as an emerging behavioral pattern in maternal experience. In pursuit of desiring a need for respect and acceptance for personal decisions and beliefs, these shared reflections offer the idea of individuals as active decision-makers rather than passive recipients of care.

► **Loss, Trauma, and Grief**

Loss, trauma, and grief were closely linked to maternal experience and emphasized history of miscarriage or infant loss. While some respondents expressed acceptance for experiences they had endured, others articulated action needed to protect women from further hardship.

"We know our baby is in heaven and at peace."

"Mothers need more support post-partum. Whether it is more family leave or doctors doing a better job of explaining the reality of life after giving birth. There is often a lot of trauma and recovery, and women are typically given a quick 6 week check and sent on their merry way."

"You should have at least 1 Cuddle Cot at all hospitals. It's not fair for the mothers of dead babies to not be able to hold and have their babies with them for however long they want. Ice bags do not work."

► **Fertility & IVF**

The ability to conceive via in vitro fertilization (IVF) as well as length of time to conceive was commonly noted among respondents. While PRAMS does not ask whether IVF was utilized to conceive, these results highlight that when prompted to discuss and reflect on maternal experience, method used for conception is top-of-mind for those who utilized IVF.

"My pregnancy was conceived by ivf. With out this medical technology we would not be able to have children."

"Went through ivf for 2 years with 4 embryo transfers and now have my miracle baby."

▶ Paid Family Medical Leave

Findings for policy recommendations emphasized leave time. NH's Paid Family and Medical Leave (PFML) law contrasts with states like MA. Of the seven comments specifically citing leave time (negatively or positively) three compared the leave time policy to Massachusetts, all comments pointing to MA's longer leave times and feelings of not being ready to return to work shortly after birth.

"NH needs to pass legislation to improve/mandate maternity and paternity leave for all residents. I work for a MA employer and got 5 months paid leave. This is so important. My husband got zero leave and had to take PTO because he works for a NH company. This is a disgrace."

These narratives highlight policy priorities and suggest a need for PFML program expansion, including mandatory, broader coverage.

▶ Social & Economic Stressors

Social and economic stressors were widespread, particularly among the topics of childcare and housing. Job instability for self and/or partner as well as general affordability struggles were also cited. Reported inability to maintain housing (i.e. kicked out) was within the first three months of pregnancy, suggesting that while housing security is important for overall maternal experience, support may be needed most during the first trimester of pregnancy. For every mention of childcare cost, respondents indicated they had generally sufficient financial means and/or had been proactive to contact daycares, however due to high cost and/or waitlists, stress of affording or securing daycare was prominent.

"I was in the hospital for a week before giving birth due to preeclampsia. My baby was born at 37 weeks but got down to 3 pounds due to a growing restriction and lack of food. I am 18 and my baby is 3 months old. I got kicked out at 2 months pregnancy, lived in the car, places where people came in with guns and drugs. It was bad but now I'm getting an apartment with my bf and cousin and we are all doing well!"

"I work nights and my husband works days as despite 2 well paying jobs we cannot afford daycare for our 3 children."

Families Flourish Northeast: Experienced-Based Co-Design using Trauma Informed Care¹⁶

Funded by: HRSA

Project leads: Julie Bosak, DrPH, CNM, Cheri Bryer, CRSW, Daisy Goodman, MPH, DNP, Meagan Adams, CHW T. Barry, Cassidy Flanagan, Victoria Flanagan, RN, M.S.

Families Flourish Northeast, a newly launching residential treatment center for pregnant and parenting women with active SUD, is designed respond to the needs of these patients while filling in a gap of care availability missing in the state of New Hampshire. Pregnant and parenting women with SUDs are faced with unique challenges in accessing treatment options and the current system for addiction treatment does not effectively meet their needs. The role that trauma plays in their condition and the difficulty of entering treatment, which could force them to be separated from their children, are some of the leading factors that treatment is abandoned or postponed.

Co-design research identified barriers to effective treatment and improved understanding of ways to engage and retain residential treatment for pregnant and parenting women with SUD. Utilizing the model of patient-centered care, the purpose of the research was to build off the experiences of the patients and providers in order to co-design the center's policies (this method is known as experience-based co-design or EBDCD) and integrate the approach of Trauma Informed Care when designing the treatment programs.

The study, funded by a grant from HRSA to Boston University School of Public Health, aimed to understand what prevents women from completing residential treatment effectively.

¹⁶"They just looked at me like I was human": The experiences of parenting women and providers with substance use disorder treatment, Bosak, J. et al., *Journal of Substance Use & Addiction Treatment*, Volume 157, 209240

The researchers conducted interviews of both parenting women with lived experience (WWLE) in residential treatment and providers who were involved in specialized residential treatment planning. 13 WWLE and 19 providers from areas serving a rural and low-income population with high rates of substance use participated.

The research revealed four interconnected themes that directly inform treatment design, each supported by compelling patient and provider experiences.

The first theme, “peer relationships provide inspiration and diminish shame,” underscored the importance of the TIC principles of peers, safety and collaboration, and mutuality.

The second theme “providing a safe space to stumble while in recovery creates a space for growth and self-efficacy” aligned with the TIC principles of safety, empowerment, voice and choice, and collaboration of mutuality.

“The team ... wanted to discharge her because of the behavior and I didn't feel like that was the appropriate action, even though that is our policy and even though she did create... a hostile environment and she did intimidate and she made some threats. I didn't feel like that was the appropriate action, because I felt like she was acting out of a trauma response and instead of discharge, I came up with an alternative plan and it was discussed and we were able to do that and that client is still here, successful now.”

- WWLE #2, peer recovery coach

The third theme, “an environment with reasonable and clear boundaries creates a protective structure for early recovery,” centered around the TIC elements of safety, collaboration and mutuality, and trust and transparency.

“I think that structure is really important for people who are living in chaos and that when somebody is very, very chaotic... structure that is defined and transparent and fair can be reassuring.”

-Provider # 94

Lastly, the fourth theme, “connections that are free from judgement facilitates more engagement and trust,” supported the need for strong human connects that support feelings of safety and acceptance for women.

“Meeting with a staff member who said...we're going to take care of you. And I said no, no I'm here about my baby, because I'm worried about that. And she's like yeah, we'll worry about that later we're gonna worry about you right now. And having someone meet me with that compassion and saying thank you for trusting me enough to tell me how you were feeling about this and what can we do?”

-WWLE #8, peer recovery coach



Table 6. Selected Themes & Actions for EBCD in relation to Trauma Informed Care

Theme	Action
Peer relationships provide inspiration and diminish shame	Peer recovery coaches and those with lived experience in specialized-care provide safe, collaborative and mutual connections for treatment retention.
Providing individuals safe space to stumble during recovery creates opportunities for growth and builds self-efficacy	Structural factors such as policy choices create an environment of safety, empowerment, voice and choice that is collaborative and mutual
Creating a non-judgemental human connection facilitates engagement in treatment and builds trust	Non-judgemental listening that provides a safe space for expression, shame, fear, anger and acknowledgement of the past, engages and retains patients in treatment.

Note: The data and quotations in this chart are part of the overall results of the study and directly quotes the themes and the quotations from the article "They just looked at me like I was human": The experiences of parenting women and providers with substance use disorder treatment, published in the Journal of Substance Use & Addiction Treatment, Volume 153, 209240

This study helped to guide the strategies and priorities of the NHPQC through an enhanced understanding of the experience of a patient with active SUD accessing and engaging in treatment.

To inform the strategic goals to foster a culture of caring, the researchers identified that a collaborative approach requires the inclusion of patients who are going through recovery and is pregnant and/or parenting.

This research supported the importance of addressing stigma, embedding harm reduction policies and the value of peer support workers. Top-down models of treatment built on stringent rules, led to more negative experiences while programs that are inclusive of patient's experiences, flexible to allow mistakes in order to ensure retention, and create more connections with peer support.

The researchers noted that some structural barriers to care require higher level policy change now identified in the NHPQC policy and advocacy priorities. These efforts center patient experiences with structural barriers to care such as insurance reimbursements requirements, to implement state-level changes that address these challenges.

Data to Action

- The data collected from this research was integral to supporting aspects of the strategic plan to develop content that addresses stigma and shame.
- The strategic plan also prioritizes the development of a robust and supported peer recovery workers program, and the development of evidence-based practices to support harm reduction.

Next Actions

The patient voice research presented in this report has moved from evidence to action — shaping not only the strategic priorities of the NHPQC but also how the organization itself operates.

Centering lived experience is no longer a research activity; it is a core practice embedded in how the NHPQC builds its coalitions, structures its task force, and co-creates improvements with communities across New Hampshire.

From Findings to Sustained Engagement

The themes identified across these projects — breakdowns in communication, gaps in mental health support, barriers driven by geography and insurance, the protective power of peer connection, and the deep need for patient agency — have directly informed eight workgroups now active within the Maternal Health Task Force. These workgroups bring together community members, providers, doulas, peer recovery workers, and community health workers to translate patient experiences into actionable strategies. Crucially, the workgroups are designed not just to act on these findings but to continue with the people who shared them.

Patient and Caregiver Participation as a Design Principle

Building on the lessons of the patient voice research, the NHPQC is formalizing how patients and caregivers participate in the work itself. This includes:

- A PQC Moms Group — a dedicated space to provide tailored support and continuous follow-up for patient participants, ensuring they feel valued, heard, and genuinely involved in improvement efforts rather than consulted once and set aside.
- Co-created educational content — working directly with people who have lived birthing experiences to develop provider training materials, so that clinical education reflects the realities patients have described rather than assumptions about them.
- Resetting power dynamics — intentionally structuring coalition meetings, task force sessions, and workgroups to foster inclusion, surface all voices, and treat community members as true co-designers rather than stakeholders to be informed.

- Community-facing dashboards and stories — combining quantitative data with the qualitative insights gathered through Photovoice, Emotional Journey Mapping, and focus groups, so that communities can see their own experiences reflected in how progress is measured and shared.

Growing the Coalitions, Deepening the Connections

In year two, the NHPQC's 11 perinatal coalitions remain the foundation of this work. Expanding those coalitions — and deepening the community relationships that make them effective — is a central priority. The Maternal Health Task Force will increase its collaboration with external partners, including DCYF, WIC, community health workers, and peer recovery programs, to leverage shared strengths and avoid duplication of effort.

The goal is a system that learns from the people it serves — continuously, not periodically. The patient voice work captured in this report is not a finished product. It is an ongoing collaboration with the NHPQC and its members to co-create change. This approach will continue to shape and sharpen the NHPQC's approach to maternal health for years to come.

Contact Us

If you are interested in joining us, please visit our website:
www.NHPQC.org

The PQC leadership team seeks to facilitate the work of this group to collaboratively improve perinatal health in the state while being responsive to funder's requirements.

Appendix

Additional Background Data

New Hampshire is a geographically mixed state with both urban centers in the south and rural, remote regions. Eight-four percent of NH landmass is considered rural, and 47% of residents live in these areas. In 2024, 73.5% of births occurred in non-rural areas, while 26.3% occurred in rural.² The state has also experienced notable demographic change: racial and ethnic diversity increased by 90% between 2010-2019. In 2024, White non-Hispanic accounted for 84.1% of NH births followed by 7.4% Hispanic, 2.6% Asian, 2.3% Black or African American and 1.2% two or more races.² Today, one parent in more than 1 in 5 births identify as other than white non-Hispanic.

Title V Assessment, NH DHHS MCH, Survey Questions

Based on your personal or professional experience, select the response that best describes how much of a concern the issue is for women who are **pregnant, planning to become pregnant, or have delivered a baby in the last 12 months** in your community or service area.

	A very big concern	Somewhat of a concern	Not much of a concern	Don't know
Access to prenatal care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to support after having a baby	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Substance use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression/anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intimate partner violence/sexual assault	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotional/economic abuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to birth control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breastfeeding support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexually transmitted infections	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smoking/tobacco use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alcohol use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social isolation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discrimination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inadequate or no insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support for dads/partners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Title V Assessment, NHDHHS, Survey Questions

Based on your personal or professional experience, select the response that best describes how much of a concern the issue is for **babies** in your community or service area.

	A very big concern	Somewhat of a concern	Not much of a concern	Don't know
Born prematurely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Born with low birthweight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Abuse and neglect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sudden unexpected death (SUID)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exposure to substances during pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exposure to secondhand smoke	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Screening for developmental delay	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Evaluation for development delay	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prenatal screening for birth defects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vaccinations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental mental illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental substance use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inadequate or no insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dental care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Table 7. Overview of the Patient Voice Research in the Maternal Health Strategic Plan (MHSP)

Outlined in the table below, we have connected the outcomes of the research to the different strategies in the MHSP. While this table is not comprehensive of the entirety of the MHSP, the patient voice work is integrated into each of the different topic areas. Additional patient voice work research continues and will inform the work and adaptations to the strategic plan as needed.

Patient Voice Research		Maternal Health Strategic plan
Project	Key Findings	Topic Area: Quality Services
		Strategy
<ul style="list-style-type: none"> • PCORI • DCYF EJM • Access Photovoice • DCYF Photovoice 	<p>Shared decision-making continues to be lacking in maternity care.</p> <p>People feel that their needs, voices and expertise are not always heard by perinatal providers.</p>	Enhance Provider-Patient Relationship Through Improved Communication and Power Dynamic
<ul style="list-style-type: none"> • All projects 	<p>A culture of caring begins by listening to the patient and hearing their experiences</p>	Co-create with those with Lived Birthing Experiences to Provide Vital Info/Insights for Provider Education to Inform Improvement Efforts
<ul style="list-style-type: none"> • PCORI 	<p>Improved community connection helps patients to make better informed decisions</p>	Address workforce challenges through the expansion of culturally and linguistically inclusive training pathways
<ul style="list-style-type: none"> • Access Photovoice • DCYF EJM • DCYF Photovoice 	<p>Though resources exist in NH communities, they are unevenly distributed and poorly disseminated.</p> <p>Patients and providers are not always aware of available resources</p>	Create and support a sustainable resource and communication system for birth Communities and Providers

Project	Key Findings	Topic Area: Maternal Health Gaps
		Strategy
<ul style="list-style-type: none"> • PCORI • Access Photovoice 	<p>Patients need better support in their homes. Patients feel isolated, especially in the postpartum period</p>	<p>Enhance home visiting and support for all postpartum patients</p>
<ul style="list-style-type: none"> • FFNE • DCYF EJM • PCORI 	<p>Peer relationships are highly valued as a way to reduce stigma and isolation</p>	<p>Expand network for peer-to-peer connections and support during pregnancy and parenting</p>
<ul style="list-style-type: none"> • TITLE V • PCORI • Access Photovoice 	<p>CHWs and Doulas help bridge families to providers/ health system</p>	<p>Support holistic transition into parenthood</p>



Patient Voice Collaboration: Why Multiple Methods

No single research approach can capture the full complexity of maternal health experiences across New Hampshire's diverse geography, demographics, and social contexts. Each method offers unique strengths:

- Statewide surveys (PRAMS & Title V) provide breadth—thousands of voices across all populations, revealing patterns and priorities at scale
- Emotional Journey Mapping captures depth—the detailed emotional arc of specific challenging and rewarding experiences like DCYF involvement
- Photovoice centers patient creativity and agency—allowing participants to control the narrative through their own images and words
- Focus groups enable real-time dialogue—letting patients and families respond to and build on each other's experiences
- Interviews create space for individual stories—particularly for sensitive topics like substance use and loss.

By combining these methods, we achieve both breadth (understanding what issues affect the most people) and depth (understanding how those issues are experienced and what solutions patients themselves envision).

Building on Existing Research Infrastructure

Intentionally collaborating with researchers across the state, NHPQC leveraged patient voice work or with established community trust. This approach:

- Honored existing relationships and avoided extractive research practices
- Leveraged existing expertise in specialized methodologies
- Accelerated timeline by building on ongoing work (PRAMS, Title V needs assessment)
- Ensured community buy-in through trusted messengers

For example, the Access Photovoice project partnered with Women of the Mountains Birth Initiative, an organization with deep roots in the North Country. The DCYF-related research partnered with peer recovery workers with lived experience. The PRAMS analysis built on an existing statewide surveillance system.