

Report: Women with Lived Experience of Perinatal Mood and Anxiety Disorders in Vermont
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With gratitude,

The Vermont Department of Health

The Vermont Department of Mental Health

Introduction:

In 2018 Vermont was awarded one of seven Maternal Depression and Related Behavioral Disorders Cooperative Agreements from the Health Resources and Services Administration. In Vermont, this funding stream became known as Screening, Treatment, and Access for Mothers and Perinatal Partners (STAMPP). STAMPP activities serve to improve the system of care for the perinatal (pregnancy through the first year postpartum) population and their children and families. STAMPP also aims to increase capacity and expertise in the perinatal-serving workforce including medical, mental health, and social service providers.

Perinatal mood and anxiety disorders (PMADs) are common, treatable, and can occur at any time during or in the first year after pregnancy. PMADs can have serious impacts on maternal health and well-being and children's cognitive, behavioral, and academic development. They can influence attendance at well-child visits, vaccination status, and child safety practices. The estimated economic burden in a one-year United States birth cohort (2017) of untreated perinatal mood and anxiety disorders from conception to five years postpartum is \$14 billion (Luca et al. 2020).

While anyone can experience a PMAD, certain individuals are at higher risk for PMADs due to factors including their life experiences, genetics, and brain biochemistry. The stressors associated with low socio-economic status significantly increase a person's likelihood of developing symptoms. Due to the American history of structural racism, members of the Black, Indigenous, People of Color (BIPOC) community are disproportionately impacted by perinatal mental health conditions, experiencing them at rates two to three times higher than white individuals.

PMADs can present with symptoms such as:

- Loss of interest or pleasure in activities that were enjoyable
- Exhausted but can't sleep
- Overwhelmed or unable to cope
- Feeling guilty, irritable, or angry
- Having unwanted or scary thoughts

The postpartum period has been identified as a particularly vulnerable time for women with mental health conditions and substance use disorder. Maternal mortality rates in the US are higher than that of all other nations of comparable wealth, and rising rates of opioid use, depression, and maternal mortality are closely connected. Studies estimate that mental health causes, including suicide and drug overdoses, account for 9-20% of maternal mortality (Margerison et al. 2022, Davis et al. 2019) and are the leading cause (16%) of preventable maternal death (Trost et al. 2021). While not the focus of this report, it's important to note that although opioid overdose deaths in the perinatal population have not been calculated comparably in every state, some researchers estimate they account for 4-10% of deaths. The CDC is implementing new surveillance strategies which should lead to improved measurement in the future (Campbell et al. 2021).

Prior to the COVID-19 pandemic, data from the Pregnancy Risk Assessment Monitoring System (PRAMS) showed that as many as one in five Vermonters suffered from symptoms of depression and/or anxiety in the perinatal period. A systematic review of the literature on mental health outcomes in pregnant and postpartum women during the COVID-19 pandemic found moderate to severe symptoms of depression and/or anxiety in pregnant or postpartum women with prevalence rates ranging between 20% and 64% (Iyengar et al. 2021). A cross-national survey during the pandemic looked at screening for post-traumatic

stress disorder (PTSD), depression, and loneliness in pregnant and postpartum women from 64 countries. The authors found elevated rates of posttraumatic stress at 43%, anxiety/depression at 31%, and loneliness at 53% (Basu et al. 2021). Our society is experiencing an epidemic of perinatal distress and mood and anxiety disorders made exponentially worse by the ramifications of COVID-19.

Methodology and Data Collection:

Statewide STAMPP stakeholders, including representation from the Advisory and Steering Committees, participated in a needs assessment process in early 2019. This group identified interviewing women with lived experience of PMADs to identify strengths, areas in need of improvement, and recommendations for the Vermont system of care for individuals with PMADs and their families as a priority project. The STAMPP cooperative agreement provided pilot program funding to four Vermont communities representing urban, suburban, and rural areas of the state: Chittenden County, Franklin County, Rutland County, and Washington County with expansion to additional regions in years four and five.

As part of their work, the regional Designated Mental Health Agencies assisted with interview recruitment. Participants were recruited via flyers, the VDH PMAD webpage, email announcements, ads on Front Porch Forum, word of mouth, and provider messaging through a variety of partners and sites frequented by pregnant individuals and young families including but not limited to: medical and private mental health provider offices, Designated Mental Health Agencies, Parent Child Centers, playgroups, parenting support groups, WIC offices, PMAD and breastfeeding community coalitions, community partners serving the perinatal population, and others.

Participants that met criteria and attended interviews in person or via phone received a gift card stipend in acknowledgement of their time and appreciation that they shared their lived experience expertise on a sensitive and personal topic. Inclusion criteria included the following:

- Vermont resident over age 17
- Between October 1, 2016 and April 30, 2020 (extended due to COVID-19):
 - Were you pregnant or did you have a baby? and
 - Did you experience depression and/or anxiety while pregnant or in the first year after having your baby?

The assessment study design and data collection plan, as well as original interview oversight, was conducted by Laurin Kasehagen, PhD, Senior Epidemiologist/CDC Designee to Vermont at the time of assessment conception. Dr. Kasehagen served as the STAMPP Evaluator through September 2020. The interview guide was created through a collaborative process with STAMPP leadership and the evaluator with input from STAMPP stakeholders statewide.

The study design and interview guide went through the Agency of Human Services Institutional Review Board (IRB) application process. This study was determined to be exempt from IRB approval due to not meeting the 45 CFR 46.102(d) definition of research. Results and recommendations will be presented to leadership at VDH and VDMH (particularly the Division of Maternal and Child Health and the Child, Adolescent, and Family Unit), as well as the STAMPP Steering and Advisory Committees, the VDH Offices of Local Health, and participating pediatric, family medicine and obstetric practices, Designated Mental Health Agencies and perinatal health/mental health coalitions (specifically in Chittenden, Franklin, Rutland, and Washington Counties). The report and any subsequent presentations will be shared with

the Project Officer and evaluation team at the Maternal and Child Health Bureau / Health Resources and Services Administration.

Interviews were conducted by two licensed clinical social workers (LICSWs) employed by the Vermont Department of Mental Health and associated with the STAMPP grant as part of the comprehensive needs assessment. Some interviews were assisted by the STAMPP Program Manager. The first interview was conducted on 2/19/20, and the last took place on 10/7/20. Three interviews were in person prior to COVID-19 with a several months break and the remainder of interviews conducted by phone during the summer of 2020 due to the COVID-19 pandemic.

Interviews were transcribed and checked for completeness. Interviews were separately coded by two STAMPP team members and/or interns, and a sample of interviews were coded and checked by the Program Manager. Qualitative data software was utilized for data analysis along with a list of themes and recommendations compiled by the lead interviewer over the course of the interviews. The STAMPP Program Manager, STAMPP Program Administrator, and other STAMPP affiliated staff compiled and analyzed data and wrote this report.

Limitations of the study design methodology:

- **Linguistic, racial, and ethnic diversity:** The interviews did not capture the perspectives of linguistically diverse Vermonters; nor did they capture race and ethnicity data. At the time of design, there were concerns around participant confidentiality due to small sample sizes, but the authors acknowledge that this is a major limitation. If given the opportunity to do this work again, the authors would engage a consultant with expertise on the topic and design a strategy to capture these unique and necessary perspectives. STAMPP leadership will explore opportunities for this work in the future.
- **Gender identity and pronouns:** The study did not recruit or disqualify people based on gender identity. Participants were not asked about their pronouns which was an oversight on the part of the study and interview guide design. No participants expressed that they would like the interviewer to use pronouns other than she/her/hers. The authors regret not asking and acknowledge that it is not the responsibility of a participant to proactively share pronouns and/or gender identity information with the study staff. The responsibility to address the topic falls on the study design and implementation team and should have been considered. In the future, this topic will be addressed proactively and inclusively. Future work should include engaging a consultant with expertise on the topic to ensure that this topic is handled utilizing best practice with the utmost sensitivity.
- **Generalizability:** The data captured represents four communities in VT and was not collected statewide. While many participants lived in rural settings, and the authors attempted to solicit a mix of urban, suburban, and rural participants, they may not represent the strengths and opportunities for improvement of the system of care across all of Vermont. The Northeast Kingdom, the most rural part of Vermont, is not represented, and the needs in that area may be different. Southern Vermont counties also did not participate in the study. Unique attributes for that region such as cross-border access to medical and mental health providers in MA and NY were not studied. Washington County participants did provide some feedback on care at Dartmouth in NH.
- **COVID-19:** At the time of the assessment design, interview guide creation, and related IRB approval in 2019, COVID-19 did not exist, and the STAMPP leadership team and authors could not have anticipated the effect of the pandemic on this project, services and supports for

pregnant Vermonters, those in the perinatal period, and Vermont as a whole. Several focus groups were in the process of scheduling but were canceled because of the pandemic. Focus groups did not resume leading to the loss of opportunity to capture the rich data that often comes from group settings. The interviews were placed on pause in spring, 2020 to accommodate safety measures regarding recruitment and interviewing participants. Once interviews resumed, they were all completed by phone which may or may not have altered participant’s willingness to be forthcoming with information.

While every attempt was made to review interviews for information shared by participants on the impact of COVID-19 on the pregnancy, birth, and postpartum experience (if applicable due to the timing of the pregnancy and postpartum period), COVID-19-specific questions were not part of the interview guide, and revising the scope of the project and interview guide was not an option due to the departure of Dr Kasehagen. When relevant, many participants shared the impact of COVID-19 on their experience with the interviewer. The authors worked to extract data related to participants’ COVID-19 experience from the participant narratives, and this information is included in the report, but we acknowledge richer data reflecting the depth and breadth of perinatal COVID-19 experiences may have been obtained by an interview protocol specific to COVID-19.

A note about language: Participants discussed their experiences with words such as “woman,” “women” “maternal,” and “mom.” As a result, we refer to participants with female signifiers when appropriate. As discussed in the limitations section above, the study did not explicitly recruit or disqualify people based on gender identity, and no participant used pronouns other than she/her/hers.

Results:

Interviews took place in four regions in Vermont: Franklin/Grand Isle County, Chittenden County, Washington County, and Rutland County. One participant received services, including doula care, and gave birth at a hospital in a region included in the study, but she resided in the neighboring county. For data analysis, we have included her in the data for the county where she received care as identifying a single person from one county would compromise her identity. In reviewing her interview, she did not discuss challenges accessing care other than occasional spotty internet, and we do not believe her location next to, rather than inside, the study catchment area impacts the data analysis or findings.

In total, 28 women were interviewed: four in Franklin/Grand Isle County, ten in Chittenden County, nine in Washington County, and five in Rutland County. The lower number in Rutland and Franklin Counties was a result of timing of the pandemic impacting capacity at the agencies to recruit.

Of the 28 participants, three did not have pre-existing mental health concerns, and 25 reported a pre-existing concern such as depression or anxiety prior to pregnancy.

Type of PMAD	YES	NO	UNCLEAR
Prenatal anxiety	20	7	1
Postpartum anxiety	24	3	1
Prenatal depression	8	19	1
Postpartum depression	18	9	1
Psychosis and OCD at any point in the perinatal period	3	25	0

Of the 28 participants, 12 women discussed their first pregnancy, six talked about a second or subsequent pregnancy, three did not share the information, and seven participants discussed their experience across multiple pregnancies that occurred in the study inclusion dates. Some participants brought up other pregnancies outside the study period when making comparisons between the care they received for each pregnancy. Two women mentioned experience with miscarriage, but this was not an interview question, so it is likely an undercount.

Screening:

Definitely screened at least one time in pregnancy or postpartum	20
Screened during pregnancy	9
Screened in postpartum period	11
Screened in pregnancy and PP	2
Screened (not clear if in pregnancy or PP)	2
Screening status unclear	7
Definitely not screened	1

Treatment:

Of the 28 participants, a majority of participants did engage in treatment including medication (14) and working with a mental health clinician (19). Some participants accessed both modalities, but many chose one or the other. Of those who accessed counseling, many of those were connected to a mental health provider by their primary care provider (PCP). It is worth noting that the Help Me Grow PMAD mental health provider resource was not up and running for the study inclusion period as it was developed in the summer and fall of 2019 with a soft launch in the fall of 2019 while the inclusion study period ended April 2020. Please see the discussion section below for more information on this resource. Of those who did access treatment:

- At least 13 of participants cited that it was easy to get connected with mental health providers
- 21 participants stated that one of their “met needs” was the therapy/mental health support they accessed

One woman stated about her perinatal mental health provider, “It began really just like therapy... she would offer what she could.... she mostly specialized in offering pharmaceutical options, and last year I was very much uncomfortable going that way, but she still saw me, and she's still listened to me. She was still very supportive of me wanting to try non-pharmaceutical options like supplementation with different kinds of vitamins and other things like that. She would look stuff up and offer me things to try.” A different participant went to Central Vermont Medical Center. “[I] had an awesome counselor who works in their women's health office, Angela Shea.... I was able to, like, meet with her all through my pregnancy...She was awesome, and I really appreciated her support.”

Telehealth:

Several participants listed telehealth appointments as a helpful option. There was one participant that had trouble with spotty internet which made it challenging at times. One participant shared her

experience with telehealth unrelated to the perinatal period (her babies were born in 2013 and 2017). She was a huge proponent of telehealth saying, “It was the easiest thing ever to have telehealth appointments,” once they became a common option due to COVID-19.

Support from providers:

We asked participants to score their perception of the support they received from different types of providers using a ten-point Likert scale. 14 out of 28 participants stated they were overall satisfied with the care they received in the perinatal period from their providers as a whole. Not all provider types sum to 28 in the table below as not all participants accessed all types of providers. Responses include:

Type of Provider	1-3 range	4-7 range	8-10 range
Obstetric MD	3	6	13
Midwife	1	2	5
PCP (internal med/family med/etc.)	1	1	5
Mental health clinician/provider	0	0	5
Pediatrician	0	0	4

Furthermore, some participants elaborated on what providers did that was received well and felt supportive:

- “I am very thankful because it was, it was extremely easy. I really felt like everybody on the team at Dartmouth took it very seriously. And then... here in Vermont, you know, they got me in, I would say, maybe two to three weeks postpartum. There really wasn't a long wait. There were no hoops to jump through, so to say. It was, pretty easy.” **Washington County/ OB Support**
- “When I went for my two-week checkup at the OB, you know, obviously like physically everything was good... they [sic] asked how I was doing, and I said [sic]that I'm finding it really difficult kind of not having that [sic], daily check in and so for a few days, the midwife asked if I'd want to have them just give me a call every day, just kind of check in and see how I was doing. I said, “Yes, that would be helpful.” We ended up doing that for a few days, and like one day I missed a call so then that kind of stopped, but, I think, someone called a few days later, and they just said, “You know do you still want the phone call,” and I said, “No, I think I'm doing better.” **Chittenden County / OB Support**
- “That's a big thing, especially when you don't know what you need. You know you can tell somebody, “I think I need this,” but if you're not entirely sure, they also do this thing that is really great. They send somebody out to evaluate the entire situation. They send three people out to you, and they sit you down and you talk about, "Okay... where are you at mentally, emotionally? And where in the past have you been mentally and emotionally? What caused the stressor? What could cause it again?" That right there is a monumental thing because not every mother is going to be able to say, "Well, I have depression and I have anxiety, and I think I need this." Some of them are just going to be like, “I have no idea. I don't know where to start,” versus if you have somebody that's been going to counseling for ten years. They're going to be like, “I know my myself enough to say this is what's going to happen, or this is potentially what could happen.” ... They are very helpful. [sic] I don't think things would be where they are today without them.” **Franklin & Grand Isle Counties / Mental Health Support / HEART Program**
- “It was easy to share with my midwife what was going on.... I guess for several reasons, she's a very nurturing person that you feel very comfortable opening up to, and she showed a lot of,

you know, care and concern and a genuine care and concern not just the head nodding. You know, secretly watching the clock waiting for you to go. And one thing I think was a huge... is that our appointments were an hour, sometimes over an hour each time.” **Chittenden County / Midwife Support**

- “The ability to have somebody come to your home, to be able to help you that way, is also a lifesaver when you are in my spot and don't have a vehicle right now, and in my spot and live 45 minutes away from [sic] your hub, so to speak.” **Franklin & Grand Isle / *author’s note that this participant is probably referring to the HREAT program but did not name it**
- “...Compassion friends: it's a group that they have in church here in Rutland with parents that they have lost kids...We go there every Tuesday once a month, the first Tuesday, and we share like how we feel and stories about our kids, but we are the youngest ones. We the only ones who lost a baby. Everybody else lost, like, a 25-year-old kid, or you know, 30... everyone's over 60. It's helpful because we can talk about it, and you know they can understand, but at the same time, we feel like [sic] they have good memories to remember, but we don't. So, it's helpful; they're really nice people and you know like, it's when we feel comfortable because we can cry there, [sic] we can express our emotions so it's pretty good.” **Rutland County / Community Support**
- “I went to all these people. My doctor was excellent... It’s hard to remember exactly what I had said to her because I wasn't really in my right mind, but I remember telling her some of the things that were bothering me, and I remember thinking I had anxiety, and she had written down my symptoms... At that point, she referred me to the psychiatrist, and I don't remember if we...discussed... ‘oh you have psychosis,’ or if [sic] that would have even made sense to me at the time because I wouldn't have even known what it was...I know she was very excellent and listening to it figuring out what it was, and getting me to the right place... I just wasn't able to access it as fast as I could have...” **Washington County / Primary Care Provider**
- “I would say Addy is a life saver. She offers to come to the house... We could do it every week but we do every other week. If I have stuff around the house or m doing pile of laundry, she folds or helps. Dishes: she helps. Keeping the child entertained: she helps. If I need a shower, she'll sit there with the children so I go take a shower... like she is a lifesaver... She’s the HEART postpartum doula. Every mother should know about that, especially on her first child and if she doesn't have support or help at home. That is a lifesaver.” **Franklin Grand Isle County /HEART Program Doula**
- “They are really lovely... I felt very cared for. I felt very supported and reassured in terms of [sic] being concerned about my daughter's health. Yeah, I feel like [sic] they were really lovely.” **Chittenden County / Pediatrician**

Barriers to accessing treatment:

The most common barriers to accessing mental health treatment discussed by participants included:

- Finding a mental health provider with whom they stated they felt a connection
- Difficulty opening up to the mental health provider
- Difficulty opening up to their medical provider about their need for mental health support
- Challenges finding a mental health provider that accepted the participant’s insurance
- Concerns about psychotropic medication
- Financial barriers and insurance
- Hard to get alone time for appointments

- Difficulty finding providers with specialization in PMADs
- Hard to find a provider in my area
- Getting providers to listen to concerns
- Hard to reach out for services
- Lack of knowledge of resources
- Lack of provider follow-up
- Lack of telehealth option
- COVID-19 safety
- Seeing different providers each time
- Inability to take time out of the day to access supports
- Timeframe of accessing supports
- Transfer of care

Additional details regarding common barriers:

One participant elaborated about the difficulty opening up to providers:

- “I feel like it's a little different for me; though. I try to be more self-aware, and I have seen people who have struggled with postpartum who don't have that same ability to be self-aware in how they're feeling. I really just kind of want to reiterate the fact of... how difficult it can be for them, [if they] don't have the support, aren't self-aware, and aren't realizing that they're not themselves... Somebody like that had gone [sic] through that meeting with my provider might have been kind of a different outcome.”

Financial barriers and insurance:

- “I guess my, my assumption would be that, like something like a crisis hotline [would be] free, and actually noticed that like my insurance looks like they're going to charge me for the calls I [made to] First Call. That's not necessarily an obstacle in the moment, but kind of after the fact, I probably wouldn't have called them if I would have known it was going to cost me money every time I talked to someone there, which could then ultimately be an obstacle for someone.”

COVID-19 safety:

- “Part of that is due to this pandemic because you know, to me, I had therapy in the past, and they have all been in person, and that has definitely been a huge help for me. When I sought it out and decided to do therapy, and support groups, and things like that [because they] are also important as far as meeting other moms with similar situations. I would have loved to meet other moms in person because you just develop friendships and have playdates and those are also good for your kids, and you meet people in your community. Those are things that are a side effect of this pandemic... Moving right before [COVID-19] to a new place, I think [it] prevented me from doing that unfortunately.”

Medication was not the right fit for some women with ten stating they were uninterested in medication treatment. In their own words, participants shared some of their reservations and concerns which mainly surrounded medication and breastfeeding:

- “No... I would not have taken any (medication) because I probably wouldn't have been able to continue breastfeeding.”
- “I feel like it was difficult in the sense of medication, I didn't really want... medication and I felt like that was big. It was kind of being more pushed on me. I, as soon as I went to my

appointment, ... met with the doctor and was talking to her about how I was feeling... she was very understanding, but she was like..., "I can definitely hook you up with a counselor that you can talk to. We have great counselors, and I can always prescribe you Zoloft" ... I believe (Zoloft), was the thing that was safe for breastfeeding... so they automatically kind of started bringing up antidepressants and trying to kind of get me to take medication, but I was breastfeeding, and I didn't want to, even though they told me that it was safe."

- "Not during pregnancy and postpartum, not like nothing for antidepressants or anti-anxiety because I was breastfeeding, and I'm very against taking medications. I haven't done anything since I was prescribed them in college, and then I stopped ... two years before I got pregnant."
- "You know, I did fill the prescription, but I have yet to actually consume the prescription just because it's not like I'm really against doing it, but I really wanted to push through on my own. And, I think at this point, I feel better about the situation and myself because I didn't start the medication. I was able to push through it on my own. And she also recommended to talk to someone as far as therapy goes."

Impact of Birth Experience on Mental Health:

Participants were eager to share the impact of their birth experiences on their mental health. Of the 28 participants, five women spoke about their complicated and traumatic birth experiences, and all cited these experiences as impacting their mental health:

- "I knew that having a midwife was my preference. I was going to have to go down to Gifford. That turned out [to be] amazing, and I'm so glad I did because I did have a complicated delivery. I trusted, I trusted them with my life, I trusted them with the baby's life, and it worked out...I just can't say enough good things about the staff at Gifford."
- "I had a traumatic pregnancy. I ended up delivering early at 34 weeks because I had preeclampsia."
- "... with my first I ended up getting blood clots and so I was in the hospital for a week... after the c-section because I had an infection. It was a mixture of an infection with my uterus and the long labor, and they think I ended up getting a blood clot."
- "I tried to deliver my daughter vaginally, and then she got stuck and I ended up with an emergency c section. It was a long, long awful labor and I almost was, like, upset with myself and so angry with myself that I couldn't do it naturally.... I beat myself up over not being able to do it. It gets me emotional talking about it."
- "I had been planning a home birth, and it was an extremely long labor. I think it was like around 50 something hours and ended up resulting in a transfer to the hospital. I ended up with a c-section. My recovery was very difficult... I was unable to, like, walk without pain for a couple of weeks, and it kind of got to the point where we were wondering if my body was healing correctly, and it was just like the complete opposite experience that I had been anticipating for my birth."

Additional stressors that impacted mental health:

Participants were very forthcoming about the challenges they faced in the perinatal period that impacted their mental health and ability and interest in seeking and accessing support such as mental health providers for therapy and/or medication and/or other concrete supports. The most common stressors listed by participants included (in no specific order):

- Financial and insurance challenges
- COVID-19
- Work stress
- Health of baby
- Personal physical health
- Finding the hospital stay stressful
- Breastfeeding
- Prior trauma
- Having additional children to care for in the home
- Managing the challenges of siblings
- Household maintenance
- Adjusting to life with a new baby

In addition, participants delved more deeply into several areas that were especially challenging for some women including:

Stigma surrounding mental health:

- “I think when you go through things like this... the first feeling that you feel is alone, and very misunderstood, and ashamed at the same time, so it's really helpful to know that other people struggle with things like that. It doesn't make you a bad mom, because I think that's one of the biggest feelings that I've had, and I'm sure other people have had that because [sic] you have so many different emotions at the time you almost feel like you're a bad mom for needing the extra help, or the extra assistance, and... your own mental health.”
- I think... the work environment because... that was just such a big problem, not having [m] job understand what [I'm] going through. And not supporting you. And then, you know, having to work so that you have insurance, so that you can get yourself help when you are not really available to work. I think that's a huge problem. So that was a big obstacle. And then, I [left and was] trying to find another job. When you're trying to find a job you know you don't go in there saying, “I have postpartum,” because, you know, people are not going to want to hire you if you come in telling them that I'm dealing with a mental illness. So then, you know, going to work another job where you also... feel like you don't really want to tell anybody what you're going through because you don't... want the stigma, or you don't feel like you're going to be able to be supported properly and you want to have a job.”
- “I wasn't connected with any [supports or treatment]. To be honest, I was really quiet about it. I think that, you know, there was a there was a big stigma attached to it. You feel like you acquire coping mechanisms and you kind of teach yourself how to handle things as they come as you know as you get older. And, you know, for a while, quote unquote, I could handle it. I could deal with it and still live a life and have a job and raise my kids. But really, I wasn't helping myself out at all.”
- “I feel like they might have not gotten the help that they needed because they could have felt a little bit more ashamed because postpartum depression and anxiety is certainly talked about but I feel like it's very taboo almost at the same time so when you do talk about exposure, and this is an uncomfortable conversation...to some extent, but I think it's important to have that conversation regardless.”

Time spent researching supports:

- “The resources were there, I guess it was there when I looked hard enough that I kind of had to do the work. For somebody who doesn't have the initiative to kind of reach out themselves, I feel like it's not always that that easy to get unless you have the right people and know the right people right at your fingertips. There [are] people who don't have support and don't have the motivation to find it or can't even realize that anything is really off with that until it's too late. I feel like it's a little bit more difficult for them to get the help that they need.”
- “I spent so much time on the phone... trying to ascertain what kind of coverage I have for what sort of things and even, you know, things like well infertility treatment was partially covered, because the clinic contracted with a surgeon that was out of network, and they were trying to bill me for the surgeon cost, so, you know, that was always an underlying stressor too, and not really, you know, having to navigate that in addition to everything else that it felt like a full time job, and at times was paralyzing like it was exhausting.”

Constant advice/judgement:

- “There's a lot of questioning what you do. There's a lot of, you know, people telling you ‘Oh well this is best,’ and that's wonderful, it might have been best for you, but how does it work for everybody else? It's not just one person. You know this experience goes beyond what you experience... everybody's different. You know, even your own.... experience is different [for different pregnancies/babies].”

Getting providers to listen to concerns:

- “Yeah, I think it was just that I was overlooked in a sense so that was a barrier in trying to get help because it was like... they would almost want to be understanding but at the same time it's almost like I got a feeling like they didn't believe me fully... When I told my nurse home visitor [sic] I had it, she was like can I bring you, because it was like she almost didn't believe me.”
- “It oftentimes didn't seem like they were really hearing me around the psychological experiences I was having. They noted it, but it wasn't really until I had a heart to heart with the midwife that ended up delivering my baby.”
- “I would say just the whole process of even getting in for an appointment or getting someone to understand what was going on with me. I just felt very alone, and like nobody was on my side, like they thought I was crazy.... I mean, that's the biggest obstacle, just getting somebody to hear me out, and help me out.”
- “I feel like it was difficult in the sense of medication, I didn't really want... medication and I felt like that was big. It was kind of being more pushed on me...”
- “I didn't feel like they were like ignoring me. I just felt like they were like, “We don't really know how to help you.” Vermont doesn't have any perinatal mood psychiatrists. Like, that's just not really... you know, I was looking up like trying to find resources and there were people in Boston, but it was like there's nobody in Vermont, so it just was hard to know where to turn to... for support beyond like the OB office because they just like didn't I think I just didn't feel like they were like ready to deal with that.”

Being flagged by providers:

- “They connected me with [Northwest Counseling and Support Services] in the beginning, and it helped, and it helped a lot towards the end... so when I mentioned it to my counselor, she took note of it, but she was worried because she's like "you can identify that you're not going to harm yourself like you don't want to do it, but those thoughts are present," which really helped me and I kind of had like a breakdown. I was like, "Oh thank God, like someone I can finally open up to," but after I had spoken, I felt like I could be open with the other people I was working with, so I had a home health nurse who came in and checked as well... When I had mentioned it to her, she red flagged me.”

*author’s note: it was unclear from the interview what ramifications resulted from the participant being “red flagged,” but the authors felt this was important to include to give voice to the participants perception of the situation.

Location challenges:

- “After my appointment with my naturopath, I just looked into potential [sic] counselors. I went into psychology today, and that's where my sister-in-law was [listed as] a therapist, and she said that she advertises... I looked up in my area, and it was mostly people in the Burlington area. I live out in [other Chittenden County town], so that's like 25 minutes away. [I'm] a little frustrated about where they are having access and having to drive all the way in there to be able to see somebody.”
- “I think [telehealth] would have been possible but I don't think it was as effective. When you are out in the middle of nowhere and your internet isn't very reliable, and you don't really have the technology to do that kind of stuff, it makes it a little difficult. Being able to see facial expressions in person... is more meaningful than seeing it through video chat. But it's an option and I, I honestly think that that's one thing that COVID is has helped with is really pushing telehealth to move forward because I don't think it has been used as much as it should or could be.”

Impact of COVID-19 on study participants:

While the timeframe for recruitment ended in April 2020 right as Vermont locked down for the pandemic, many participants interviewed in April 2020 and beyond shared information and reflections on the impact that COVID-19 had and was having on their perinatal period or life in general if their baby was now older. The authors made a decision to attempt to capture this information in this report; even though, it was not part of the original interview guide, and no COVID-19 specific questions were asked.

COVID-19 is having a staggering impact on maternal mental health. Physical distancing and shelter in place mean that many pregnant and postpartum women do not have access to critical in person support from friends and family. In research from the first 2 years of the pandemic, many women reported they no longer felt comfortable engaging in coping strategies such as time outside in nature, gym based and outdoor exercise, or attending pleasurable events and gatherings (Basu et al. 2020). Prenatal and mental health appointments may have moved to telehealth, and in person appointments may have been limited to the just the pregnant person with rules changing regularly based on COVID-19 rates in communities. In some cases, hospitals are still limiting the number support people allowed at the birth to one person. The virus has added additional socioeconomic stress and compromised childcare taxing an already precarious balancing act for many pregnant women and families. While the country as a whole may be reducing COVID-19 precautions as we collectively remove masks during low community transmission times and increase in person contact including at medical appointments, vulnerable

pregnant and postpartum women with infants that cannot be vaccinated, may be uncomfortable easing up on restrictions, and some may even find the lifting of restrictions stress inducing as they feel less protected while still vulnerable. All of these stressors result in significantly increased risk of symptoms of anxiety and depression in the perinatal population.

On March 13, 2020, Governor Scott declared a state of emergency, and March 24, 2020, Governor Scott issued a “Stay Home, Stay Safe” order and directed the closure of in-person operations for all non-essential businesses to slow the spread of the COVID-19 virus and protect the public. While the interviewers did not specifically have questions with regards to COVID implications, some of those interviewed did mention the challenges that COVID-19 presented for them as they navigated pregnancy or the postpartum period or both. Of the 28 people interviewed, at least four were pregnant during COVID and 13 were postpartum. For some of the interviewees, the timeframe of their pregnancy and postpartum periods is unclear. Of the 11 people who were clearly not pregnant during COVID-19, there were five who were also not postpartum. There are six people whose postpartum period was during COVID-19; even though, they were pregnant pre-COVID-19. One of these people mentioned that they ended up having the baby at Dartmouth because the UVM Medical Center would not take them because of restrictions caused by the pandemic, but they did not share the extenuating circumstances for utilizing either medical center.

A total of 16 people mentioned COVID-19 at some point during their interview. As mentioned above, the majority noted the challenges they faced especially included navigating telehealth appointments and in person appointments without a support person. Many also mentioned fears surrounding the health of their baby with a new and deadly virus circulating in the community. One participant mentioned fear that the stress of COVID-19 might impact the number of pre-term babies while another person who was not pregnant or postpartum during COVID-19 reflected that telehealth appointments were not an option before COVID-19 necessitated them. While difficult to systematically evaluate COVID-19 implications without a standard set of questions, themes of fear and uncertainty were prevalent.

The authors of this report were able to review interviews and determine the following:

Status of Participant	YES	NO	UNCLEAR
Pregnant during COVID-19	4	11	13
Postpartum during COVID-19	12	5	11
Mentioned COVID-19 in the interview	16	12	N/A

COVID-19 and Screening:

Some of those interviewed were screened for PMADs either in the prenatal or postpartum period during the COVID-19 pandemic. However, none of the participants referenced difficulty with screening either on the phone or via a telehealth appointment. Of those who were in the postpartum period during COVID-19, at least seven were screened during that time. At least 3 of the participants pregnant during COVID-19 were screened prior to the birth of their baby.

Of those participants that referenced the impact of COVID-19 on their pregnancy or postpartum experience, the following experiences were shared:

- Participants found telehealth visits easy for the most part. While some expressed that it may have been nice to go to an office, participants had fears surrounding being in any shared spaces with their newborn and found telehealth less stressful
- Most participants who referenced COVID-19 said they wished telehealth options were available to them prior to COVID-19 due to the ease of doing appointments from their house/in their own space with a newborn
- One participant who worked outside the home mentioned that she was not granted as much leave as she requested and was uncomfortable going back to work at the height of COVID-19
- Some participants felt their medical providers did not follow up as often during COVID-19. They posited that perhaps the change was due to the stress COVID-19 placed on healthcare providers
- Participants encountered challenges in working remotely with no childcare when childcare providers shut down in the spring and summer of 2020, and some expressed they felt it was not safe to send their babies and children to childcare or back to childcare
- Not surprisingly, participants expressed fear of testing positive for COVID-19 while pregnant
- Some participants shared that their partner was not allowed at well baby health supervision appointments during COVID-19 causing them stress

An often-cited barrier to care during the COVID-19 pandemic was the restrictions placed on people allowed to attend medical appointments. One mother was not allowed to bring her infant with her to her post-partum visit at six weeks due to the practice's COVID-19 safety protocol. If a person does not have a trusted alternate caregiver for the baby, stringent rules such as these can prevent access to vital appointments where physical and mental health concerns are addressed. Participants also expressed that limitations placed on partners attending prenatal appointments and changing rules in offices and hospitals were stressful.

Recommendations:

Study participants were asked to share their recommendations on improving the system of care and supports in pregnancy and the postpartum period. Below are these suggestions. Some of their suggestions were made by multiple participants, and those are toward the top of the list. In addition, the main interviewer recorded her reflections after interviews and created a list of common themes and suggestions that she observed across interviews. There is overlap in the recommendations from participants and the themes the interviewer included, but that repetition serves to reiterate the importance of addressing these challenges when designing and improving the system of care.

Recommendations from participants:

- More time off from work
- Paid family leave
- Additional support focused on dads
- Increase provider knowledge of supports and services like Good Beginnings
- Providers should reach out to all families with a new baby across all sectors (mental health, pediatrics, obstetrics, social supports, etc.) proactively offering holistic resources so new moms/parents don't have to initiate contact
- There is lots of attention on the baby at pediatrician appointments, but there should be more attention paid to moms at the early well baby visits
- Evening support groups to accommodate working moms/parents

- Virtual postpartum check-ins with moms
- More screening throughout pregnancy and before moms leave the hospital
- Providers should offer more information on preparing for the postpartum period, what to expect, and resources
- Better communication across provider offices
- Offer more of Sandy Wood's Mindfulness classes; and offer this sort of class to all pregnant and parenting families
- Grocery delivery service

Reflections from Interviewer:

The study's lead interviewer conducted the majority of interviews and recorded her reflections, creating a list of common themes and suggestions observed across interviews as well as recommendations for the system of care including:

- Paid parental leave for both caregivers (if there are two caregivers) available to all people caring for a newborn including foster parents and adoptive parents and grandparents/other relatives if they are the main caregiver for the baby
- Warm handoff with the Women's Health Initiative (WHI) and/or other social work or nursing staff for a dedicated conversation regarding PMADs including signs & symptoms, prevalence, resources, etc.
- Show the PSI or Support Delivered video at every birth hospital and have parents view it prior to discharge
- Include information on resources for post-birth recovery including physical therapy for pelvic floor, massage therapy, and other physical recovery resources in addition to mental health supports
- Local resource packets at hospital discharge containing resources and guidance (some hospitals already do this)
- There is a disparity between the level of planning and preparing for the baby's birth with multiple prenatal visits over the course of the pregnancy compared to the limited postpartum follow up of one or two visits. Women described feeling forgotten after birth
- There is a need for more directed postpartum care planning. Consider adopting Virginia's Postpartum Care Plan
- Participants suggested a need for classes about postpartum and newborn care to better prepare for the reality of the postpartum period and caring for a neonate. This was anxiety provoking for some women
- Women mentioned they would have liked more conversations with providers specifically about mental health and the discussions should start early in the pregnancy with materials to take home at more than one visit
- There is a need for more and better integration of mental health services in medical provider settings and a focus on holistic wellness
- Training for providers that PMAD symptoms and presentations are varied. For instance, a woman may look like she's doing well but would screen positive for high depression or anxiety on a screener and need resources and referrals
- Repeated screening throughout entire pregnancy and postpartum period
- Implement a 2-week postpartum visit as standard of care at all Vermont OB and midwife practices

- Participants expressed a need for the option of in-home mental health services (COVID-safety allowing), and those that participated in this treatment reported high levels of satisfaction
- Doulas should be widely available and not cost prohibitive. Consider covering doula services with insurance
- Participants expressed that there should be an emphasis on providers offering supports and services often and proactively in the postpartum period rather asking women to “reach out if needed.” Participants suggested brief telehealth visits could serve this purpose
- Some participants found it hard to find time to clarify insurance coverage details and schedule appointments

Conclusions and Next Steps:

This report provides the opportunity to highlight changes to the system of care for the perinatal population to address the challenges and recommendations listed above that have occurred since the interviews were conducted in 2020 while also acknowledging that there is more work to do. While it is unfortunate that the timing of the COVID-19 pandemic and resulting capacity strain at the Vermont Departments of Health and Mental Health delayed this report, this delay provided the opportunity to highlight STAMPP-facilitated and post-pandemic changes to the system of care for the perinatal population.

All recommendations above should be given consideration, and STAMPP leadership, Advisory Committee, Steering Committee, stakeholders, and champions should reflect on these recommendations and utilize an upcoming Steering Committee meeting to address the challenges outlined in the report and identify action items with consideration of feasibility, short, medium, and long-term goals, and policy implications. Below, the authors highlight some of the successes of the last (almost) four years of STAMPP and address challenges ahead. While not yet a comprehensive plan, it will serve as a springboard for discussions with STAMPP stakeholders and inform sustainable next steps.

STAMPP has improved access to perinatal mental health providers and the capacity of the profession to treat PMADs across the state by providing PMAD training to over 500 mental health clinicians, medical providers, and social service providers through Postpartum Support International, Project ECHO, Grand Rounds sessions, VCHIP efforts, and other training and educational opportunities.

In order to address barriers to accessing PMAD trained mental health providers, the perinatal mental health provider resource and referral list at Help Me Grow connects Vermonters in need of a mental health provider with expertise and training in PMADs to a care coordinator who will work with them until they are connected to a provider with availability in their area or over telehealth that takes their insurance, is accessible given their transportation needs, practices different therapeutic modalities, has expertise in trauma, and can match across multiple other categories. This comprehensive PMAD resource database allows HMG staff to help families navigate and address barriers to accessing services and treatment. HMG staff universally screen for social determinants of health to identify other needs in the family and provide additional referrals to basic needs resources, legal or financial services, and more. HMG staff close the loop with referring providers (with client permission), providing updates to the client’s medical, mental health, and other social service providers, to ensure they are notified the client was able to access and connect to needed services.

In partnership with the Maternal and Child Health Division, the Vermont Child Health Improvement Program (VCHIP) facilitated formal partnerships across Perinatal Improvement Project teams known as

the Perinatal Quality Collaborative-Vermont (PQC-VT). The PQC-VT collaborative approach has engaged key perinatal providers (birth hospitals, outpatient providers, community-based organizations and families) to advance perinatal outcomes and priorities including: increased screening, referral, and treatment for PMADs and substance use disorders, provision of technical assistance in screening implementation, tool choice, and workflow optimization, aligned quality improvement activities and outcome monitoring, and outreach, education and other supports to practices/partners seeking assistance.

The Designated Mental Health Agencies piloted the Parents and Babies (formerly Mothers and Babies) program to bring an evidence based PMAD prevention and treatment model to providers working with perinatal populations such as home visitors, home health nurses, Parent Child Center staff, DA non-clinical staff, Head Start, other Children's Integrated Services staff, and other partners. This intervention provides services that can prevent and treat mild to moderate symptoms of PMADs while providers work to get clients connected to a mental health provider with PMAD expertise. Furthermore, as a prevention modality, this model relieves pressure on the overtaxed mental health system by preventing some clients from needing a higher level of care. Additionally, the DAs are implementing innovative programming such as in person and virtual support groups, Circle of Security programming, a doula program, work with BIPOC Vermonters including adapting Parents and Babies to be culturally inclusive and respectful of Abenaki Vermonters, and resources for the rural perinatal population. They have cemented stronger relationships with other service providers in their communities, and their community perinatal mental health coalitions have matured to continue the work once the STAMPP cooperative agreement sunsets.

In April 2022, STAMPP launched Support Delivered, an umbrella of supports and services available to pregnant and postpartum Vermonters. Support Delivered offers an array of Vermont-based perinatal mental health resources including information about how to get connected to mental health clinicians with training and/or specialized expertise in perinatal mental health through Help Me Grow, virtual clinical support groups, parenting support groups, information on wellness and stress reduction, and other offerings (both in-person and virtual). The Support Delivered communications campaign includes a social media campaign and public service announcements, promotional ads for hospital birthing units, and promotional materials for medical, mental health, and social service providers and community partners serving the perinatal population. Materials are being translated to ensure access for all Vermonters.

- Posters for provider office settings
- A provider one pager with resources regarding referrals and treatment
- A Perinatal Psychiatric Consultation Service one pager
- Postcards for the Help Me Grow VT (HMG VT) referral resource
- Brochures for families that give an overview of PMADs and services and supports available in VT

A participant mentioned Vermont's lack of perinatal psychiatric mental health providers. While, like most states, Vermont does not have enough perinatal specific psychiatric providers to meet the need, Vermont does have perinatal psychiatrists and psychiatric nurse practitioners that see patients. In addition, Vermont has a Perinatal Psychiatric Consultation Service which provides consultation, technical assistance, and training to medical and mental health providers providing care to the perinatal, pre-conception, and breastfeeding population. Consultation Service providers provide consults on individual patients and build capacity in medical and mental health providers to treat the perinatal population. STAMPP has supported other Vermont medical and mental health providers in attending the

psychopharmacology training at Postpartum Support International. Through Support Delivered, STAMPP is increasing knowledge of the Perinatal Psychiatric Consultation Service across the state to ensure providers are aware of this service and utilize it to assist in effectively treating patients.

Many women that were interviewed stated reluctance to take psychotropic medication while pregnant and/or breastfeeding. While individual choice and preference should take precedence, and medication is not necessary or the right decision for all women experiencing PMADs, more education for providers and pregnant and postpartum women and families as well as the public on the safety and efficacy of many medications may encourage more nuanced provider-patient conversations on the topic. The Psychiatric Consultation Service, together with ongoing educational opportunities for providers, will continue to share information, best practices, and resources on this topic. Furthermore, the mother's and baby's physical and psychological wellbeing are at risk when experiencing untreated PMADs meaning forgoing medication, in some circumstances, is not without risks as well. Much care should be taken to not guilt or shame women into making medical decisions, but a well measured factual discussion of the risks and benefits of medication is only possible when providers and patients have accurate, up to date information.

The implications of difficult and traumatic births as well as infertility, miscarriage, and loss on the mental health of postpartum women should not be underestimated. STAMPP will continue to provide education and resources to providers and the perinatal population on these topics, but more can be done. Targeted learning sessions, additional supports and check ins by medical, mental health, and other support providers for women post-loss and/or post-birth, telehealth access, and targeted services with an eye toward raising awareness of and enhancing existing services will be explored in the final years of STAMPP to support this population. STAMPP aims to collaborate with experts in the field and has reached out to Empty Arms for additional partnership on the topic of loss in the perinatal period, and the Perinatal Psychiatric Consultation Service has information and resources for providers who wish to enhance their understanding of the topic.

In terms of other initiatives to increase access for supports and referrals to services, Vermont is a pilot state for HRSA's new National Maternal Mental Health Hotline launching in spring 2022. This service provides free and confidential support, resources, and referrals to pregnant and postpartum individuals facing mental health challenges and their loved ones. Hotline counselors provide support via phone and text in English and Spanish. Interpreter services are also available in 60 languages. Vermont's Postpartum Support International chapter continues to offer regional warmlines throughout the state staffed by volunteers who offer local support, information, and resources and are a strong advocate for the needs of the perinatal population and providers caring for pregnant women and families.

Several participants as well as the lead interviewer, lead author of this report, and STAMPP stakeholders have shared their wish for more universal adoption of the two-week postpartum visit at medical practices and more routinized connection to the Women's Health Initiative (WHI) social workers at practices where this is an option. Some in Vermont are already providing the two-week visit, and many practices have WHI social workers available, but how practices utilize their WHI team differs by practice. STAMPP will explore barriers and opportunities for the adoption of these recommendations with providers and patients starting with practices that are currently implementing these activities to gain insight into the benefits and challenges such as capacity, workflow, etc. Policy and insurance considerations will be explored.

STAMPP pilot communities have explored or implemented doula programming to great success, and several participants identified doulas as an important part of their pre and postnatal care and part of their plan to reduce their risk of PMADs. In Vermont there is a swell of interest in accessing funding to make doula access universal and/or more accessible across Vermont regardless of income and/or insurance status. The Vermont Department of Health along with a multi-disciplinary group of perinatal professionals and doula leaders and advocates have been exploring several avenues for doula compensation including grant funding, funding through a Community Health Worker model, and advocacy group led interest in accessing Medicaid coverage for doula services.

Supports for dads and other non-gestational caregivers such as grandparents, foster and adoptive parents, stepparents, and second parents in same-sex relationships are available through Support Delivered and several innovative organizations such as Dad Guild. At the moment, most Dad Guild services are in Chittenden County, but the organization is seeking to expand. Good Beginnings is another organization that supports all parents in the Washington County and Upper Valley communities. STAMPP leadership and partners should continue to build their relationships with these valuable organizations. Efforts should be made to cultivate additional connections with community-based agencies to elevate successful programming.

There is more work to do. While Vermont has reasons to be proud such as expanded Medicaid coverage for pregnant people and one of the lowest uninsured rates for children in the nation with over half of Vermont children enrolled in Medicaid and only 1% of the state's children remaining uninsured (2021 Vermont Household Health Insurance Survey), healthcare costs are a concern for many Vermonters in the perinatal period. Deductibles and high deductible plans, out of pocket costs, and the challenges facing the underinsured can break many family budgets and be devastating to some resulting in substantial medical debt and even bankruptcy for a portion of families. The price of prenatal care and childbirth (and follow up care if there is a complication or medical condition with the pregnant person or baby), is challenging to many families. The costs don't stop at delivery as child healthcare costs can also put families at financial risk. The US and Vermont should continue to explore policies that not only ensure insurance coverage for pregnant people (and all Vermonters), but also make it affordable.

One participant shared her surprise at receiving a bill for accessing crisis services. First Call's funding includes Administrative Medicaid dollars to support basic crisis programming, and as a result, they do not usually bill for phone calls to the service. However, if a person requires a full crisis assessment and/or meets with the crisis team repeatedly including filling out paperwork and sharing insurance information, insurance will sometimes be billed. While many agencies do not pursue payment from families if they don't pay the bill, the system can be confusing to pregnant people and families. The STAMPP team should discuss this topic with stakeholders to identify any avenues for better communication.

Federal and state policy implications such as guaranteed paid family leave for all parents and caregivers regardless of gestational status, affordable and accessible childcare, summer care, and after school care, a strong social safety net especially regarding housing and food security, and other concrete needs will support families as they welcome and raise their new babies. Advocates and policy makers should collaborate to address shared goals and visions.

Finally, we must continue to acknowledge the impact of COVID on the perinatal population and vulnerable infants as well as those who cannot yet be vaccinated such as young children and medically vulnerable members of our community of all ages. While some in society have moved on from strict pandemic safety measures, and others are starting to join them, parents of infants and young families

are anxious and feeling left behind or forgotten as many in society embraces a return to some semblance of pre-pandemic life. Considerations of ways to continue to support the perinatal population through and post pandemic must be stay front and center, and efforts to address PMADs, reduce social isolation, and increase wellness should take into consideration the perinatal population's experience at this stage of the pandemic.

In closing, if you are a provider, pregnant or postpartum Vermonter, or a loved one of a person in the perinatal period in need of resources and/or help connecting to supports and services including assistance accessing mental health providers with specific expertise in treating PMADs, assistance is available across Vermont at supportdeliveredvt.com and can be accessed at Help Me Grow by completing an [online referral form](#). Or, you can:

- Call 211, option 6
- Text HMGVT to 898211
- Email info@helpmegrowvt.org

Citations:

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