

Alachua County
Perinatal
Mental Health
Coalition



ACPMHC



ALACHUA COUNTY
MATERNAL MENTAL HEALTH NEEDS ASSESSMENT
Phase I
FINDINGS REPORT

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EXECUTIVE SUMMARY

Introduction

Depression and anxiety are at their highest rates in the lifecycle during the childbearing years from puberty to menopause. Perinatal mental illnesses are a leading public health concern. Nationally, up to one in five women (approximately 20%) will experience what is known as a Perinatal Mood or Anxiety Disorder (“PMD”) related to the time of pregnancy and the year after delivery; including those who experience perinatal loss.

PMDs have been identified in women of every race, ethnicity, culture, income level and education level during childbearing age. Men and partners also experience PMDs at the rate of approximately one out of every ten.²⁹ Minorities, women with comorbidities of pregnancy and those with limited resources are at heightened risk for mental health complications during the perinatal time frame. To our knowledge, no previous study has been carried out in Alachua county or Florida to specifically identify the status of maternal mental health.

You cannot tell by looking. Every woman needs to be informed, screened and offered appropriate services.

More than 900,000 parents in the United States experience depression or other perinatal mood disorders annually.²⁶ This makes PMD the leading health complication during the pregnancy and postpartum timeframe

In the most severe cases, women are taking their lives and at times, the child’s life, while suffering in silence and believing they are alone with no relief to be found.

The prevalence rate of PMD surpasses the combined rate of gestational diabetes and preeclampsia.

In Florida more than 200,000 babies are born each year. In Alachua County, Florida, almost 3,000 babies are born annually. The combined two-generation costs of untreated perinatal mood disorders for both are: \$900,000,000 (Florida) and \$12,600,000 (Alachua County).⁹

The Perinatal Mood and Anxiety Disorder (PMD) spectrum is often lumped into one term, postpartum depression; however, this term does not capture the fact that other mood disorders and anxiety also occur during pregnancy and after. The newest research available on perinatal anxiety reveals prevalence rates at least as high as for depression.



The risk factors and causes that lead to PMDs are complex and numerous; however, it is imperative to identify those who are at risk and ensure timely and appropriate support and resources. Alachua county residents are largely uninformed as to risk factors for PMDs.

When left unrecognized and untreated-

Unrecognized and untreated perinatal mental illnesses have been linked to low rates of prenatal care, increased rates of preterm birth, stillbirth, perinatal death and neurodevelopmental disorders.³² The cognitive, social and emotional development of a child born to a mother or parents with untreated PMDs are put at great risk.¹⁶ Mothers experiencing PMDs are at heightened risks for numerous adverse health outcomes including preeclampsia, cardiovascular disease and



death.¹⁸ Impaired maternal/child bonding and attachment, lower rates of breastfeeding, strain on relationships and families, maternal death and factors leading to involvement of the legal system (divorce, child protective services) as well as significant financial expenses are all related to unrecognized and untreated PMDs.^{15, 37}

Oftentimes, the functioning of the woman or man affected impairs the ability to parent appropriately, work or perform other essential roles and functions of daily living.

As if experiencing a PMD alone isn't debilitating enough, women with comorbid conditions including history of trauma, high risk pregnancies, perinatal loss, substance abuse disorders^{35,38} and intimate partner violence have compounded risk factors.^{23,39}

Awareness, prevention, early identification and the referral process are all very important elements in addressing this major public health concern. It is in

this context that the community needs assessment was carried out by the Alachua County Perinatal Mental Health Coalition. The purpose of this undertaking is to assess the current local understanding of perinatal mental illnesses, identify gaps, and develop recommendations for addressing PMDs for healthier families in Alachua County, FL.

Barriers currently exist in Alachua County for consumers and providers:

- Stigma and fear surround issues related to perinatal mental illness and are largely the culprit for many never receiving help.
- In large part, there is a current lack of understanding for the public and providers about the spectrum of disorders, risk factors, prevalence, treatment options- and to the extent specialized resources do exist for Alachua County residents, there is little knowledge about how to access them or what is provided.
- Alachua County medical providers who responded indicated a lack of training about PMDs and lack of referral sources for their perinatal patients, specifically those who lack resources to pay for specialized care.
- Both consumers and providers report lack of communication and coordination between different providers and referral sources. During the needs assessment launch meeting open to the public, community members listed as a priority a need to address this lack of coordination and communication.
- Local listening efforts of this assessment found a gap between what is reported to be provided in our community and community members reporting they cannot find services. This appears particularly true for those with less resources to pay for specialized mental health services.

The two birthing hospitals in Alachua County graciously participated. Both report current absence of recommended training for nurses,

lactation consultants and social workers in maternal mental health. Neither currently report having protocol for providing emotional support for parents of NICU babies. Neither are currently equipped to provide best practice care to patients with severe PMD symptoms, including properly trained staff.

The consumer respondents were not representative of the total population in Alachua County. This is a large area of importance and a considerable barrier to be addressed moving forward in consideration of methodology in future needs assessments. This was the first time our community was engaged to participate in a needs assessment focused on this specific area.

SUMMARY OF RECOMMENDATIONS

The following are recommendations arrived upon following identification of existing barriers:

- **Develop an AWARENESS campaign** specific to the populations represented in Alachua County, FL.
- **Address and improve early IDENTIFICATION of PMDs** through establishing recommendations for

Encourage all providers interfacing with perinatal women to provide awareness information to women and men during pregnancy & postpartum.

universal screening and patient education on risk factors and resources for treatment.

- **Develop and employ evidence-based continuing EDUCATION** and training opportunities on an ongoing basis on perinatal mental health for providers and professionals who interact with the perinatal population. While OBGYN and Midwives are the primary source of care for perinatal women in Alachua County, other providers including but not limited to pediatricians, lactation consultants, doulas, service

providers such as WIC and home visiting programs are also urged to support screening and education efforts. The ACPMHC will address adoption or creation of a toolkit for providers including evidence-based recommendations of care.



- **Establish recommendations** for specialist mental health providers serving the perinatal population.
- **Develop and expand evidence-based support networks** to provide peer support groups and other modes of peer support for parents. Currently there are two monthly support groups in one location. Alachua County includes several rural areas without access to the centralization of services in Gainesville. Support groups for parents in rural areas should be addressed in addition to effective and appropriate support for minority populations in Alachua County.
- **Consider a specialized CENTER for collaborative care** to address perinatal mental health conditions, including families who have recently adopted, experience perinatal loss; high-risk pregnancies and substance abuse. *Prioritize* the coordination and follow-up process from screening to referral and treatment/support delivery and follow up.

Adopt strategies to address the needs of pregnant woman and new moms with other co-morbidities.

National recommendations urge a specialized, multidisciplinary approach for effectively addressing PMDs.

- **Establish evidence-based recommendations for hospitals and birthing centers** caring for the perinatal population, including birth and

Florida has zero specialized inpatient programs equipped to properly serve women with severe perinatal mental illness.

mother/baby units, NICU, Emergency Department and Psychiatric units.

- **Address protocol and services for those who require hospitalization** with respect to those who experience severe PMD symptoms including psychosis.
- **Measure changes in awareness, screening and treatment.** The ACPMHC encourages greater community participation and support for goal setting related to measuring outcomes from Phase I to Phase II MMH Needs Assessment to be completed in the year 2020.

Opportunities for the future.

We wish to express sincere thanks to each individual, provider and organization/entity who helped make this first inquiry possible.

The ACPMHC encourages greater community partnering and collaboration moving forward. From this Phase I assessment, we acknowledge the small response rate of Phase I of this assessment. This represents a major gap in understanding in more specific terms the prevalence of perinatal mental illness and how it is managed in Alachua County, Florida. The success in identifying the scope of the issue lies in greater participation from providers and organizations serving pregnant and postpartum women and their families.

Goal setting will take place next before moving forward. We invite community stakeholders to join us. The ACPMHC will pursue Phase II of the MMH Needs Assessment to be completed by the

year 2020. Alachua County has a wealth of resources, higher education institutions and organizations committed to a healthy community. We are uniquely positioned as a leader in our state to address perinatal mental illnesses. The ACPMHC is committed to creating synthesis with those serving the purpose of a healthier Alachua County.



Introduction

The overall incidence of depression during adulthood is staggering, affecting more than 16 million Americans each year. The World Health Organization reports women experience higher rates of depression than men. The incidence of experiencing a mental health complication is heightened during the childbearing years.¹⁴ Nationally, up to one in five women will experience a Perinatal Mood or Anxiety Disorder or PMD¹ related to the time of pregnancy and the year after delivery; this includes those who experience perinatal loss. Further, national numbers reveal less than 50% of women are screened for PMD²⁸; the number of those affected is likely higher than the documented incidence rate.

Approximately 900,000 parents experience PMD each year in the United States; this includes those left out of the CDC numbers but who experience perinatal loss²⁶. This makes Perinatal Mood and Anxiety Disorders the number one health complication related to pregnancy and the postpartum timeframe (**this surpasses the combined rate of gestational diabetes and preeclampsia**). PMDs have been identified in women of every race, ethnicity, culture, income level and education level during childbearing age. Men and partners also experience PMDs at the rate of approximately one out of every ten²⁹.

Incidence rates are unknown in Florida at large and specifically in Alachua County; it is in this context the Alachua County Perinatal Mental Health Coalition made a decision for this needs assessment. The Alachua County Perinatal Mental Health Coalition (ACPMHC), established in 2015, is a 501(c)(3) nonprofit. The mission of the ACPMHC is to improve awareness of Perinatal Mood and Anxiety Disorders (PMD) in Alachua County, to expand resources and support systems for those at risk for PMD in our community, and to provide professional development resources to increase provider screening and referrals.

The ACPMHC was invited to join 2020 Mom ACTION Project as an early adopter site exploring the status of maternal mental health. ACPMHC joined five other pilot and early adopter sites across the U.S. beginning in late July, 2016. 2020 Mom has provided a series of webinars, toolkits and phone calls to help guide the process of this needs assessment. 2020 Mom is a nonprofit in California originally “founded in 2011 as the California Maternal Mental Health Collaborative and evolved into a national organization with a mission of closing gaps in maternal mental care through education, advocacy and collaboration.”



¹ The term perinatal mood and anxiety disorders, maternal mental health, and perinatal mental illnesses are all widely used, often interchangeable terms nationally. For the purposes of this report, we will refer to this spectrum as perinatal mental illness or PMD.

This is the first phase of the community needs assessment exploring the mental health needs of perinatal women and the current levels of awareness, services and resources in Alachua County, Florida. The assessment took place between July, 2016 and March, 2017. We found three specific limitations of this project: lack of funding; relative short amount of time for Phase I, and response rates that do not represent a majority of the population or provider community in Alachua County. It is notable that this community assessment is the first known to have taken place in Alachua County and Florida focusing on perinatal mental illness and maternal mental health. We understand this first phase of “scratching the surface” on awareness in our County presents its’ own limitations.

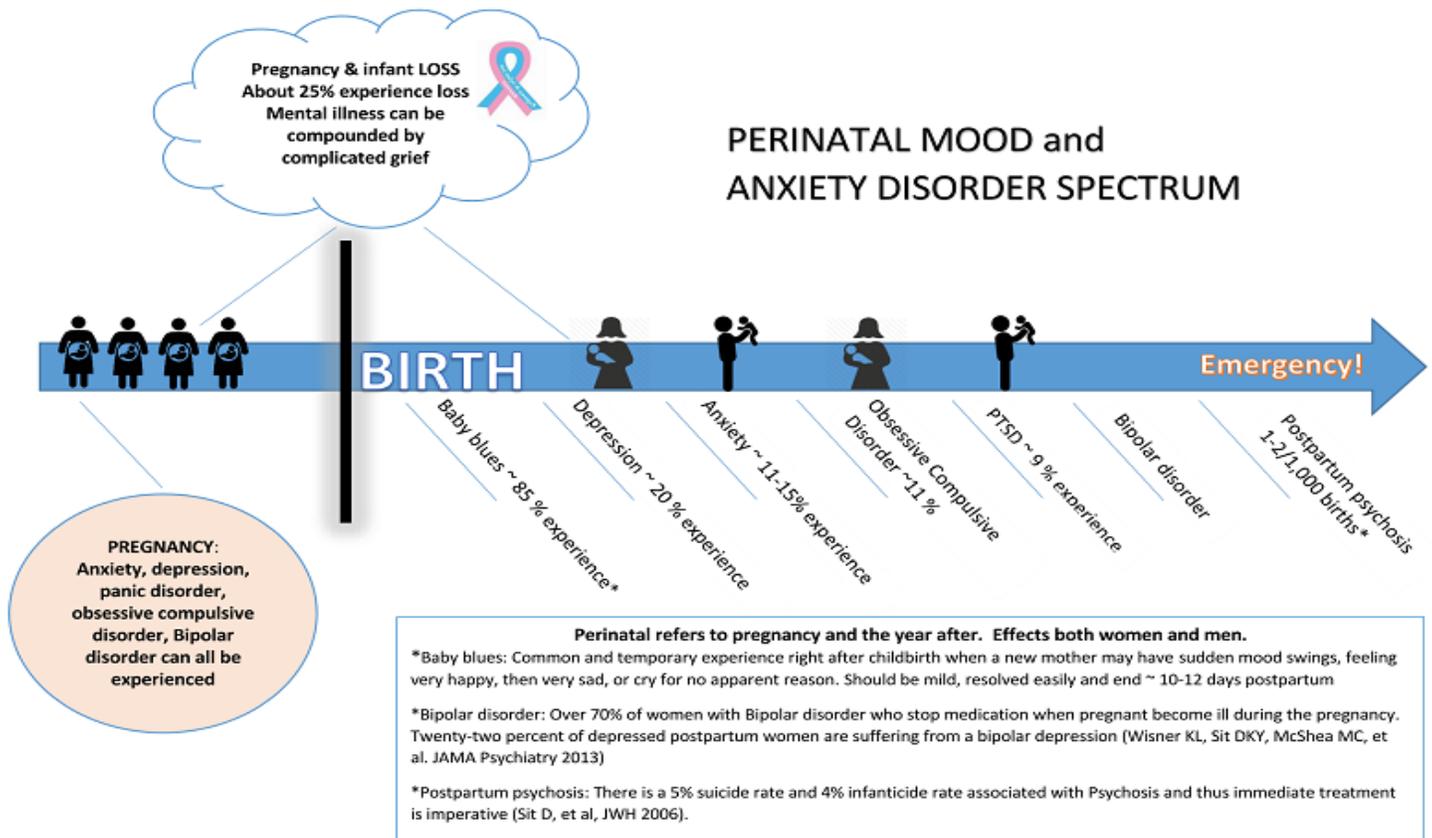
Purpose of the Needs Assessment

- Provide an overview of the epidemiology of perinatal mental illness with respect to any available statewide and national data.
- To review data and make recommendations to effectively identify perinatal mental illness in Alachua County, FL.
- To identify current gaps in awareness, education and evidence-based service provision.
- To make recommendations for local planning and strategy formulation.
- To serve as a leader for the State of Florida in addressing perinatal mental illness at a broader level.

The ACPMHC invited the existing mailing list of stakeholders to form a Workgroup for the needs assessment. The formed Workgroup met a total of 16 times between August, 2016 and March, 2017; approximately half of these meetings were webinars led by 2020 Mom and attended by Workgroup co-chairs. Stakeholders of the ACPMHC mailing list were invited to participate throughout other portions of the process as well. Existing stakeholders were also encouraged to invite and refer other interested community members, providers and organizations. The Workgroup was guided by two co-chairs, Patricia Durning and Lauren DePaola. The co-chairs were also joined by a University of Florida MPH Candidate student, Cara McDonnell, as well as volunteer Workgroup members throughout the County. The Workgroup met to review gathered secondary and primary data, solicit information from community members, review relevant literature, and make recommendations from assessment data gathering and analysis. The following report and recommendations are the result of this voluntary and collaborative work process of those interested and committed to understanding the status of Maternal Mental Health in Alachua County, FL.

Review of Literature

Perinatal mood and anxiety disorders are a *spectrum* of illnesses, as shown in Figure 1 below, that include the following during pregnancy: Depression, Anxiety, Panic Disorder, Obsessive Compulsive Disorder, Bipolar spectrum Disorder. PMD in the postpartum period include Depression, Anxiety, Panic Disorder, Obsessive Compulsive Disorder, Bipolar spectrum Disorder, Postpartum Posttraumatic Stress Disorder and Postpartum Psychosis.



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Figure 1, Perinatal Mood and Anxiety Disorder Spectrum.

The risk factors and causes that lead to perinatal mood disorders are complex and numerous; however, it is imperative to identify those who are at risk and ensure timely and appropriate support and resources.¹⁰ A short list of known risk factors include:

- personal or family history of mental illness
- single parent or strained relationship/domestic violence
- low levels of social support/recent move/immigration & displacement
- unplanned pregnancy/teenage pregnancy/unwanted pregnancy
- early childhood trauma
- sexual abuse history
- recent adverse or stressful life events (move to new location, loss of job, loss of family member, pregnancy loss)
- socioeconomic factors
- cognitive & interpersonal factors (expectations of parenthood; “type-A personality”)
- Complications of pregnancy/birth/breastfeeding
- History of hormonal sensitivity
- Chronic sleep disruptions

See Figure 2, Summary of Emotional Complications During Pregnancy and the Postpartum Period below for a comprehensive list of the spectrum, prevalence, risk factors and symptoms.³³ MCPAP for Moms helps front-line providers identify and address the mental health and substance use concerns of their pregnant and postpartum patient. This program is a leader in the U.S. for development of tools for providers working with the perinatal mental health population.

Summary of Emotional Complications During Pregnancy and the Postpartum Period

	Baby Blues	Perinatal Depression	Perinatal Anxiety	Posttraumatic Disorder (PTSD)	Obsessive-Compulsive Disorder	Postpartum Psychosis
What is it?	Common and temporary experience right after childbirth when a new mother may have sudden mood swings, feeling very happy, then very sad, or cry for no apparent reason.	Depressive episode that occurs during pregnancy or within a year of giving birth.	A range of anxiety disorders, including generalized anxiety, panic, social anxiety and PTSD, experienced during pregnancy or the postpartum period.	Distressing anxiety symptoms experienced after traumatic event(s).	Intrusive repetitive thoughts that are scary and do not make sense to mother/expectant mother. May include rituals (e.g., counting, cleaning, hand washing). May occur with or without depression.	Very rare and serious. Sudden onset of psychotic symptoms following childbirth (increased risk with bipolar disorder). Usually involves poor insight about illness/symptoms, making it extremely dangerous.
When does it start?	First week after delivery. Peaks 3-5 days after delivery and usually resolves 10-12 days postpartum.	Most often occurs in the first 3 months postpartum. May also begin during pregnancy, after weaning baby or when menstrual cycle resumes.	Immediately after delivery to 6 weeks postpartum. May also begin during pregnancy, after weaning baby or when menstrual cycle resumes.	May be present before pregnancy/birth. Can present as a result of traumatic birth. Underlying PTSD can also be worsened by traumatic birth.	1 week to 3 months postpartum. Occasionally begins after weaning baby or when menstrual cycle resumes. May also occur in pregnancy.	Typically presents rapidly after birth. Onset is usually between 2 – 12 weeks after delivery. Watch carefully if sleep deprived for ≥48 hours.
Risk factors	Life changes, lack of support and/or additional challenges (e.g., difficult pregnancy, birth, health challenges for mom or baby, twins). Prior pregnancy loss. Dysregulated baby-crying, feeding, sleep problems.	Life changes, lack of support and/or additional challenges (e.g., difficult pregnancy, birth, health challenges for mom or baby, twins). Prior pregnancy loss. Dysregulated baby-crying, feeding, sleep problems.	Life changes, lack of support and/or additional challenges (e.g., difficult pregnancy, birth, health challenges for mom or baby, twins). Prior pregnancy loss. Dysregulated baby-crying, feeding, sleep problems.	Lack of partner support, elevated depression symptoms, more physical problems since birth, less health promoting behaviors. Prior pregnancy loss. Dysregulated baby-crying, feeding, sleep problems.	Family history of OCD, other anxiety disorders. Depressive symptoms. Prior pregnancy loss. Dysregulated baby-crying, feeding, sleep problems.	Bipolar disorder, history of psychosis, history of postpartum psychosis (80% will relapse), family history of psychotic illness, sleep deprivation, medication discontinuation for bipolar disorder (especially when done quickly). Prior pregnancy loss. Dysregulated baby – crying, feeding, sleep problems.
How long does it last?	A few hours to a few weeks.	2 weeks to a year or longer. Symptom onset may be gradual.	From weeks to months to longer.	From 1 month to longer.	From weeks to months to longer.	Until treated.
How often does it occur?	Occurs in up to 85% of women.	Occurs in up to 19% of women.	Generalized anxiety occurs in 6-8% in first 6 months after delivery. Panic disorder occurs in .5-3% of women 6-10 weeks postpartum. Social anxiety occurs in 0.2-7% of early postpartum women.	Occurs in 2-15% of women. Presents after childbirth in 2-9% of women.	May occur in up to 4% of women.	Occurs in 1-2 or 3 in 1,000 births.
What happens?	Women experience dysphoric mood, crying, mood lability, anxiety, sleeplessness, loss of appetite, and irritability. Postpartum depression is independent of baby blues, but baby blues is a risk factor for postpartum depression.	Change in appetite, sleep, energy, motivation, and concentration. May experience negative thinking including guilt, hopelessness, helplessness, and worthlessness. May also experience suicidal thoughts and evolution of psychotic symptoms.	Fear and anxiety, panic attacks, shortness of breath, rapid pulse, dizziness, chest or stomach pains, fear of detachment/doom, fear of going crazy or dying. May have intrusive thoughts.	Change in cognition, mood, arousal associated with traumatic event(s) and avoidance of stimuli associated with traumatic event.	Disturbing repetitive thoughts (which may include harming baby), adapting compulsive behavior to prevent baby from being harmed (secondary to obsessional thoughts about harming baby that scare women).	Mood fluctuation, confusion, marked cognitive impairment. Bizarre behavior, insomnia, visual and auditory hallucinations and unusual (e.g., tactile and olfactory) hallucinations. May have moments of lucidity. May include altruistic delusions about infanticide and/or homicide and/or suicide that need to be addressed immediately.
Resources and treatment	May resolve naturally. Resources include support groups, psycho-education (see MCPAP for Moms website and materials for detailed information) and sleep hygiene (asking/accepting other help during nighttime feedings). Address infant behavioral dysregulation -crying, sleep, feeding problems- in context of perinatal emotional complications.	For depression, anxiety, PTSD and OCD, treatment options include individual therapy, dyadic therapy for mother and baby, and medication. Resources include support groups, psycho-education, and complementary and alternative therapies including exercise and yoga. Encourage self-care including healthy diet and massage. Encourage engagement in social and community supports (including support groups) (see MCPAP for Moms website and materials for detailed resources). Encourage sleep hygiene and asking/accepting help from others during nighttime feedings. Address infant behavioral dysregulation -crying, sleep, feeding problems- in context of perinatal emotional complications. Additional complementary and alternative therapies options for depression include bright light therapy, Omega-3, fatty acids, acupuncture and folate.				Requires immediate psychiatric help. Hospitalization usually necessary. Medication is usually indicated. If history of postpartum psychosis, preventative treatment is needed in subsequent pregnancies. Encourage sleep hygiene for prevention (e.g., consistent sleep/wake times, help with feedings at night).

¹ Adapted from Susan Hickman, Ph.D., Director of the Postpartum Mood Disorder Clinic, San Diego; Valerie D. Raskin, M.D., Assistant Professor of Clinical Psychiatry at the University of Chicago, IL ("Parents" September 1996)

² O'Hara MW, Wisner KL. Perinatal mental illness: Definition, description and aetiology. Best Pract Res Clin Obstet Gynaecol. 2013 Oct 7. pii: S1521-6934(13)00133-8. doi: 10.1016/j.bpobgyn.2013.09.002. [Epub ahead of print]

Figure 2. Summary of Emotional Complications During Pregnancy and the Postpartum Period

Perinatal mental illnesses present tremendous public health challenges spanning from the individual woman, her child, her family, communities and society at large. It is widely known that unidentified and untreated perinatal mood disorders can result in very serious adverse effects to the health and functioning of the mother, infant, and the family.²¹

Each year approximately 2800 births take place in Alachua County.⁵ **The approximated two-generation annual financial burden in Alachua County, Florida for unrecognized and untreated perinatal mood disorders is \$12,600,000.** Factored into these costs for the mother include lack of productivity, missed days from work, increased use of emergency health services. Costs associated with the child include increased medical/behavioral/educational costs and projected increased lifetime cost factors, including use of greater amounts of emergency services, associated co-morbidities, and potential for loss of productivity.⁹

Perinatal mood disorders are very treatable by a mental health professional with additional training once recognized; however, approximately only 20% of all women experiencing a PMAD are identified. Reasons including lack of awareness across the general public and providers, stigma and fear, and lack of training for professions interfacing with parents during the perinatal time frame all contribute to the high percentage of those never identified and/or treated.²⁷ Through the data collected in Alachua County, similar reasons have been revealed.

Gaining national urgency

Historically lumped into one term, “postpartum depression,” in recent years the spectrum of mood disorders during pregnancy and after, as well as their detrimental effects have gained further attention and recommendations from the United States Preventative Services Task Force as well as revised recommendations of the American Congress of Obstetrics and Gynecology have recently pushed further attention. In the USPSTF 2016 Recommendation Statement, Siu and colleagues from the USPSTF recommend “screening for depression in the general adult population, including pregnant and postpartum women,” and indicate that “screening should be implemented with adequate systems in place to ensure accurate diagnosis, effective treatment, and appropriate follow-up.”¹¹

The May, 2015 Committee Opinion of the ACOG reported, “It is important to identify pregnant and postpartum women with depression because untreated perinatal depression and other mood disorders can have devastating effects on women, infants, and families;” and goes on to say, “Although screening is important for detecting perinatal depression, screening by itself is insufficient to improve clinical outcomes and must be coupled with appropriate follow-up and treatment when indicated; clinical staff in obstetrics and gynecology practices should be prepared to initiate medical therapy, refer patients to appropriate behavioral health resources when indicated, or both.”¹²

The American Academy of Pediatrics recognized maternal depression can have “serious adverse effects on the mother and child relationship, resulting in an environment that can disrupt the infant’s development. Infants who live in a neglectful or depressed setting are likely to show

delays in development and impaired social interaction.” The AAP goes on to recommend the Pediatric provider’s role is uniquely situated to be a partner in identification and prevention by using validated screening tools at the 1, 2, 4 and 6 month well child visits and is described as a “best practice for PCPs caring for infants and their families.”¹³

Mental illness during pregnancy and the postpartum period present very serious health implications for the mother, child, partner and family, in addition to burdens on communities at large. Unrecognized and untreated perinatal mental illness has been linked to low rates of prenatal care, higher rates of preterm birth, stillbirth, perinatal death and neurodevelopmental disorders. The cognitive, social and emotional development of a child born to a mother or parents with untreated perinatal mood disorders are put at risk. Mothers experiencing perinatal depression are at heightened risks for numerous adverse health outcomes including preeclampsia and cardiovascular disease and death.¹⁸ Impaired maternal/child bonding and attachment, strain on relationships and families, maternal death and factors leading to involvement of the legal system (divorce, child protective services) as well as significant financial expenses are all related to unrecognized and untreated perinatal mental illnesses.^{15,37}

Risks of untreated perinatal mood disorders

Specific prevalence rates of the spectrum of Perinatal Mood Disorders in Florida and specifically in Alachua County are largely unknown because of the current lack of implementation and tracking of the recommendations for universal screening by providers serving women and men during the perinatal time frame. To our knowledge, no studies have been undertaken in Alachua County focused on this leading public health issue. **The 2010 Florida PRAMS report indicated 58.8% of new mothers in Florida experienced symptoms of postpartum depression while only 9.5% sought professional help.** It is also notable that the 2010 report revealed no differences in symptoms experienced according to education level. Existing research reveals underage, single/unmarried, low income and minority women are at heightened risk for experiencing a Perinatal Mood Disorder. Alachua County population includes 30.1% minorities as well as 42% of births taking place to single women and 9% of births to teen Moms. Twenty-five (25%) percent of Alachua County’s population is at or below the Federal Poverty Level.⁶

Alachua County has approximately 2800 live births each year.⁵ In line with known prevalence rates, this would mean at least 560 women and men experience perinatal depression annually and at least two episodes of postpartum psychosis requiring emergency hospital services take place each year. This does not account for those who experience pregnancy and stillbirth loss.

While exact data is unknown to the authors of this report, at least two postpartum suicides related to postpartum depression came to the attention of the Alachua County Perinatal Mental Health Coalition during the undertaking of this needs assessment. Nationally, some states have added mechanisms to document violent deaths of the postpartum period on state death certificates and during maternal mortality reviews. Florida currently reports suicide as a “not-pregnancy-related death.” From 2009-2014, the incidence of suicide has consistently increased, with last data gathered revealing 8% suicide rate. A 2011 study in the United States

of the National Violent Death Reporting System found **“that pregnancy-associated homicide and suicide are important contributors to maternal mortality and confirm the need to evaluate the relationships between socio demographic disparities and IPV with pregnancy-associated violent death.”**²¹

Alachua County does not currently have appropriately trained emergency medical service personnel or hospital accommodations to serve perinatal women presenting to emergency services or with thoughts and intention of harming themselves or with severe postpartum depression or psychosis. Florida lacks these specialized hospital services at large. The closest inpatient facility with trained staff and accommodations suitable to not further harm mother/infant bond is at University of North Carolina Chapel Hill. Their perinatal psychiatric inpatient unit was the first of its’ kind. In their brochure of what to expect, they list the following in addition to stating how their staff are trained and how they involve family with education on perinatal mood disorders: *“following assessment, treatment will include medication management, supportive therapy, education for you and your family, Occupational therapy, Recreational therapy (to include yoga, relaxation and biofeedback sessions) as well as spirituality and nutritional counseling. Comfort measures on the unit include private and semi-private patient rooms with gliders for pumping and/or nursing, protected sleep times, and extended visiting hours to maximize positive mother-baby interaction.”*⁴⁵

Providers and consumers alike have many questions related to psychotropic medication and with respect to pregnancy and breastfeeding. Many women with chronic mental illness stop taking their psychotropic medication when they become pregnant due to their own concerns or uninformed medical providers about potential harm to the developing fetus, and this underlies the high rates of relapse in pregnancy.⁴² In Alachua County, focus group participants reported medical providers most often recommending discontinuing and abstaining from any psychotropic medication during pregnancy and many had the same recommendation with respect to lactation. Others report their medical provider simply prescribed a medication and no further follow-up was done until their annual checkup. Focus group participants also discussed the negative pressures experienced from family, friends, and the community and culturally with regards to breastfeeding, sleep and perinatal mental illness.

Women suffering from mental illness who become pregnant are at a heightened risk of obstetric complications with poorer outcomes for themselves and their babies. It is therefore clear that women with mental health problems have specific obstetric and psychiatric treatment needs during the perinatal period, and this care should be delivered in a structured and cohesive manner. In Alachua County, additional education for medical providers and the medical community at large with respect to evidence-based recommendations of psychotropic medications during pregnancy and lactation will greatly benefit the health of Moms and babies. Such education does not currently exist in Alachua County.

Comorbidities of pregnancy and postpartum

Perinatal mood disorders and substance abuse share correlations.³⁸ “National survey data suggest that new mothers have high prevalence of alcohol and illicit drug use. Depression correlates with substance use, and new mothers with postpartum depression (PPD) may be at high risk for substance use.”³⁵ In Florida, NAS has increased from 592 (of 231,417) live births in 2008 to 1,411 (of 213,237) live births in 2011.³⁶ A comprehensive approach for assessment and treatment through behavioral and psychosocial methods have shown effectiveness for reducing substance use and improving outcomes for babies.

The literature review reveals perinatal loss, which is loss of an infant due to miscarriage, stillbirth or neonatal death is a very important comorbidity contributing to PMDs.⁴³ Loss during pregnancy happens to about one of every four women. The national rates of overall perinatal loss is 6.9 for every 1,000 live births. Perinatal loss is recognized as a traumatic life event and women who miscarry, endure stillbirth or neonatal death have a higher risk of developing postpartum depression (Hughes, et al, 1999). Twenty-nine (29.1%) percent of Alachua County respondents suffered a loss, only 20% of those who suffered a loss report receiving emotional support from the community.

Women are at greater risk for domestic partner violence during pregnancy and the postpartum time frame, with a 2013 systematic review finding “high levels of symptoms of perinatal depression, anxiety, and PTSD are significantly associated with having experienced domestic violence.”²³ In Alachua County in 2015 there were 1,511 cases of domestic violence reported.⁴⁴ The Status of Women and Girls in Alachua County 2014 Report cites the following correlation, “where there are more calls to law enforcement for domestic violence, there are also more reports of child abuse.”²⁴ It goes on to connect the dots of exposure to domestic violence to poor outcomes for brain development, behavior, health and cognitive problems later in life. While the 2014 report makes large strides for identifying health related factors for Women and Girls in Alachua County, it does not state connections to mental health during the perinatal time frame or life span. This is an element that cannot be separated from overall health outcomes for our community. A collaborative partnership for future reports to include the mental health of those women and girls during the childbearing years could benefit the women and girls of Alachua County.

Infants of parents experiencing postpartum depression are at greater risk for injury and death. Abusive Head Trauma (AHT) or Shaken Baby Syndrome is a leading cause of infant deaths with approximately 1300 cases per year and about 25% of those cases ending in death and the other 80% leading to lifelong disabilities. The number one trigger for parents is inconsolable crying. Infant crying increases and peaks between one to two months before decreasing. Parental exhaustion has been identified as a predictor of postpartum depression, and persistently crying infants are at a higher risk for shaken baby syndrome or other forms of child abuse.^{34,41}

Alachua County's infant mortality rate has remained higher than the Florida rate from 1994-2015.

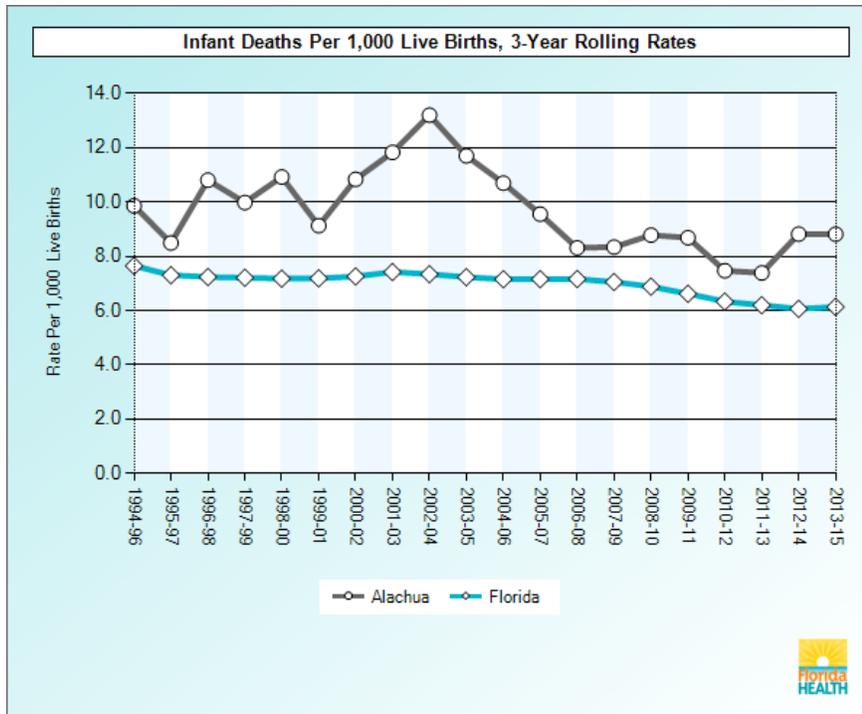
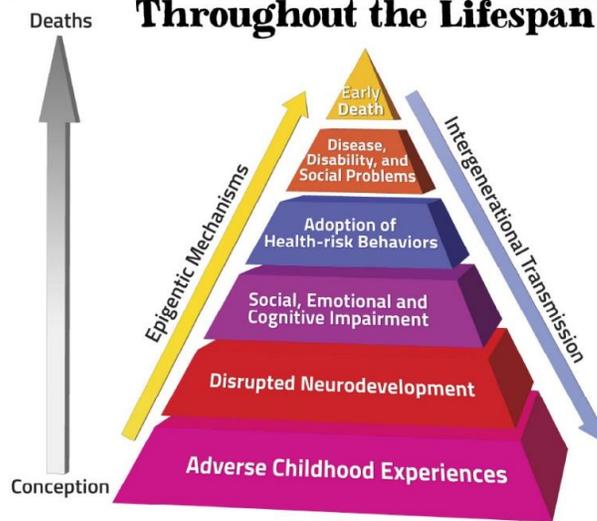


Figure 3. Infant Deaths Per 1,000 Live Births, 3-Year Rolling Rates

Postpartum PTSD is classified as a real or perceived trauma during labor or postpartum, it occurs at a national rate of about 9%. Those who have a history of abuse or trauma, specifically sexual abuse are at heightened risk for developing Postpartum PTSD. Adverse childhood experiences such as abuse or neglect have adverse effects on mother-infant bonding and heighten risk for developing Postpartum Depression and Postpartum PTSD.⁴⁰

Other women report feelings of powerlessness, and poor support or communication to be contributing factors related to the birthing experience. Those who experience obstetrical complications or have a newborn receiving care in the NICU also have higher prevalence of experiencing symptoms of Postpartum PTSD. Alachua County consumer respondents reveal 43% experienced what they describe as a traumatic birth experience.

Mechanisms by which Adverse Childhood Experiences Influence Health and Well-being Throughout the Lifespan



Slide Courtesy of Rob Anda, MD, MS

Figure 4. Adverse Childhood Experiences Influence Health and Well-being Throughout the Lifespan

PERSONAL STORIES & PERSPECTIVES

"I thought I had everything covered when I got pregnant with my second child since I had navigated my first pregnancy fairly well, and thought I knew what I was doing for the most part. But pre- and post-partum anxiety doesn't care what kind of support system you've set up; you feel anxious and alone nonetheless. For me, the anxiety came with really disturbing intrusive thoughts of my kids being hurt or abducted. The fear and panic I felt were real, and I couldn't stop replaying thoughts of their abduction in my mind over and over again. It got to the point where I couldn't be alone with both of my kids at all without having an anxiety attack. About four months after my son was born, I went to the Perinatal Mental Health Conference in Gainesville and started to tear up immediately during presentations, knowing now what was affecting me. I called a resource from the Conference the next day and began counseling. Without the local resources to treat it, I don't know if and when I would have felt comfortable being with my kids again and not constantly worrying about something awful happening to them."

Emily

"I was diagnosed with Bipolar disorder after having my first child. It left me running scared from my baby boy and husband of 15 years. It has been brutal. At one point before I was diagnosed, law enforcement was called by my family who were concerned about me and unsure of what was going on or what to do. It also included a hospitalization where I was told I didn't need to be because I seemed more normal than the regular patients. Since diagnosis and proper care, I have met so many women who describe similar feelings of isolation and despair. Something more needs to be done."

Sarah

"I didn't realize that I needed mental health support until I was halfway through my pregnancy with my second child and started having stressful flashbacks of my first child's birth. In hindsight, I wish I had sought support with my first child, especially during the immediate postpartum period. I also experienced several losses in between my first and second child and could have benefited from support then as well. Motherhood can be scary and isolating at times-- Mental health services specific to women's needs during the reproductive years are essential and often absent in many communities. We are very fortunate to have such services here in Gainesville."

S.L.

I thought I was prepared for pregnancy and parenthood. I had people around me and enough money for what we needed. No one ever told me about anxiety and depression related to pregnancy that can last into parenthood. I never saw anything about risk factors. I was scared to leave my house. I was scared my baby was going to stop breathing at any moment. I was angry at my boyfriend and would lash out in anger, wondering why I ever wanted to become a Mom. At my worst, I considered taking the entire bottle of Xanax my doctor phoned in to the pharmacy. When my baby was four months, a friend connected me to a local support group she was going to. This was the FIRST time I realized I wasn't going crazy, I wasn't alone and I could find help.

Kelly

I had no idea getting pregnant and having a baby would include attempting suicide, being hospitalized but getting no help, having my marriage break up, losing my job and DCF entering my life. None of this was in that book "What to Expect," it wasn't talked about during prenatal classes or at my doctor's office. I just want to be a good Mom to my daughter.

Ashley

Secondary data

The Alachua County Perinatal Mental Health Needs Assessment Workgroup used multiple methods to gather data, starting with a review of available data relevant to maternal mental health in Alachua County. Secondary data sources included those published by the US Census Bureau, the US Centers for Disease Control and Prevention, the Florida Department of Health, WellFlorida, and the University of Florida databanks. The information was then analyzed and summarized to provide an overview of demographics, geographic area, general status of maternal and child health, and the incidence of maternal mental health disorders. Of note, there are some superficial discrepancies in the data from various sources due to differences in data collection timing and procedures. We attempted to organize the information presented below in such a way as to focus on the best source of each data type (e.g., US Census for overall population data). During the process of gathering the secondary data for this needs assessment, it was evident that there is a lack of data regarding PMDs on all levels: national, state, and local. Moreover, the majority of the sparse data focuses on postpartum depression rather than the full spectrum of PMDs.

OUR COMMUNITY: ALACHUA COUNTY DEMOGRAPHICS

Alachua County is in North Central Florida and includes the incorporated communities of Alachua, Archer, Gainesville, Hawthorne, High Springs, La Crosse, Micanopy, Newberry and Waldo. Gainesville is the largest city, and it is where most of the services and resources are located. According to the **2010 U.S. Census Bureau report**⁶ (the most recent available), the population of Alachua County is 247,336 and the population estimate for July 1, 2015 is 259,964. The population per square mile is approximately 282.7 in Alachua County compared to 361.02 in Florida and 88.93 in the United States.

In 2010 there were 100,516 Alachua County households, of which 36.4% included a married husband and wife; there were 53,500 families. Women made up 51.6% of the population, and children under five years of age comprised 5.3%. The racial makeup of the county at the time of the census was 69.9% White, 20.3% Black or African American, 0.3% Native American, 5.4% Asian, 0.1 % Pacific Islander and 1.7% from “other” races; 8.4% were Hispanic or Latino (Figure 1).

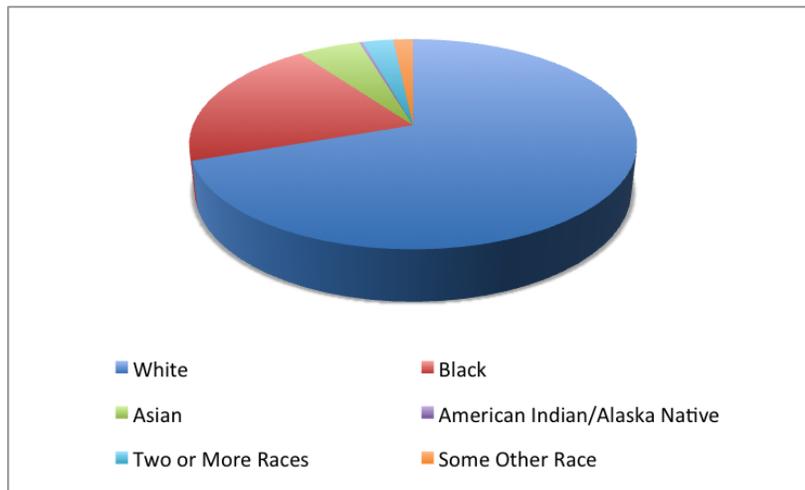
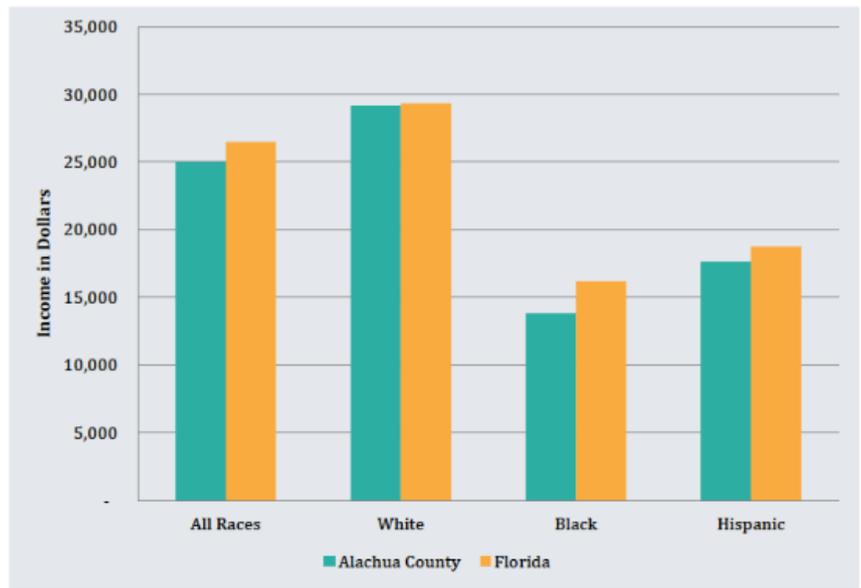


Figure 5. Racial composition of Alachua County (2010 U.S. Census report)

According to the US Census Bureau estimates for 2010 to 2015, among the Alachua County residents at least 25 years old, 92.6% had a high school diploma and 41.6% had a bachelor’s degree or higher. The median household income from 2011 to 2015 (in 2015 dollars) was \$25,498, and 21.1% were living in poverty. The proportion of the population in this region who were under age 65 and without health insurance was 12.6%.

The **US Centers for Disease Control and Prevention** provides a **Community Health Status Report**², which compares Alachua County to peer counties, resulting in ratings of “better,” “moderate,” and “worse” on various indicators. Alachua County fares worse than peer counties on a number of variables associated with increased risk of PMDs, including single-parent households, poverty, violent crime, uninsured, pre-term births, and inadequate social support.

In 2016, **WellFlorida Council** conducted an **Alachua County Children’s Services Needs Assessment**⁸; this report, while focused on children’s services, also provides data on potential risk factors for PMDs. According to the WellFlorida results, the rate of poverty was higher in Alachua County than in the State of Florida (22.9% vs 15.2% of households); the rate varied by race, with a higher rate of Black households than White households living in poverty (36.9% vs 21.4%). Income levels by race are presented in Figure 2. Within the county, there was variability in rates of households in poverty by zip code, with the highest rates in 32603 (47.7%), 32601 (38.5%), and 32607 (33.2%). These rates may be somewhat inflated due to the rates of full-time students without income who reside in these zip codes.



Source: Table 66, Alachua County Children's Services Technical Appendix 2016, prepared by WellFlorida Council.

Figure 6. Per capita income by race (2010-2014 estimates; WellFlorida Council)

Under a Community Health umbrella, **UFHealth Shands** provides a Needs Assessment Platform that includes a **SocioNeeds Index**; this is calculated by Healthy Communities Institute using data from the Nielsen Company, 2017. The map in Figure 3 visually depicts areas of socioeconomic need related to poor health outcomes in Alachua County.

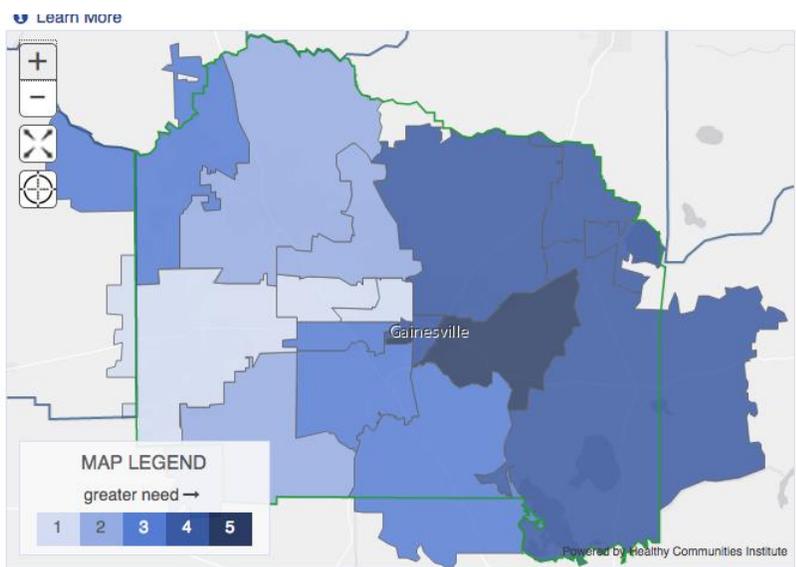


Figure 7. 2017 SocioNeeds Index (UFHealth Shands)

OUR MOTHERS AND BABIES: DATA RELEVANT TO MATERNAL MENTAL HEALTH

Healthy People 2020 is an initiative under the United States Department of Health and Human Services that lays out a 10-year plan of national goals and objectives that have been identified as leading indicators of health; the goal of the initiative is to improve the health of the community at all levels³. One of the leading indicators included is maternal, infant, and child health. Under this indicator, there are two objectives that are associated with PMDs: 1) increase the proportion of women giving birth who attend a postpartum care visit with a health worker, and 2) decrease the proportion of women delivering a live birth who experience depressive symptoms. Despite this national platform for issues of maternal mental health, there is still a lack of relevant data available. This lack of data is especially true for the state of Florida. When searching for maternal mental health data in the state of Florida, most of the information focuses on general variables associated with PMDs (e.g., access/utilization of health care services, general health status indicators, and insurance rates) rather than incidence or prevalence rates for PMDs. Nevertheless, there is some data available from which to generate hypotheses about MMH needs in our community.

The **US Centers for Disease Control and Prevention** and state health departments have been conducting the **Pregnancy Risk Assessment Monitoring System (PRAMS)**¹ since 1987. This surveillance project has been collecting “state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy.” Unfortunately, not all states collect the full range of data, and there are some limitations in the data available for our state. Furthermore, the same variables have not been included in the survey each year.

The 2013 Florida PRAMS survey in Florida was completed by 1,320 new mothers, with the sample representing 215,194 live births in the state during 2013. The questions and data cover three sections: before pregnancy, during pregnancy, and postpartum and infant health. There are questions in each of these domains germane to PMDs, and the results are summarized in Figure 4. Although the questions do not all directly address PMD symptoms or diagnoses, 6 to 10 percent of respondents endorsed experiencing some depression or anxiety during at least one of the time frames. In addition, 75.3% of the respondents indicated that they had experienced at least one significant stressor (from a provided list) during the 12 months prior to their baby’s birth. When explored within demographic categories, the rates of endorsement of for the two postpartum symptom questions (i.e., feeling down, depressed, or hopeless; having little interest or pleasure) were highest among respondents in the following categories: non-Hispanic Black, 19 years old or younger, less than high school education, and unmarried.

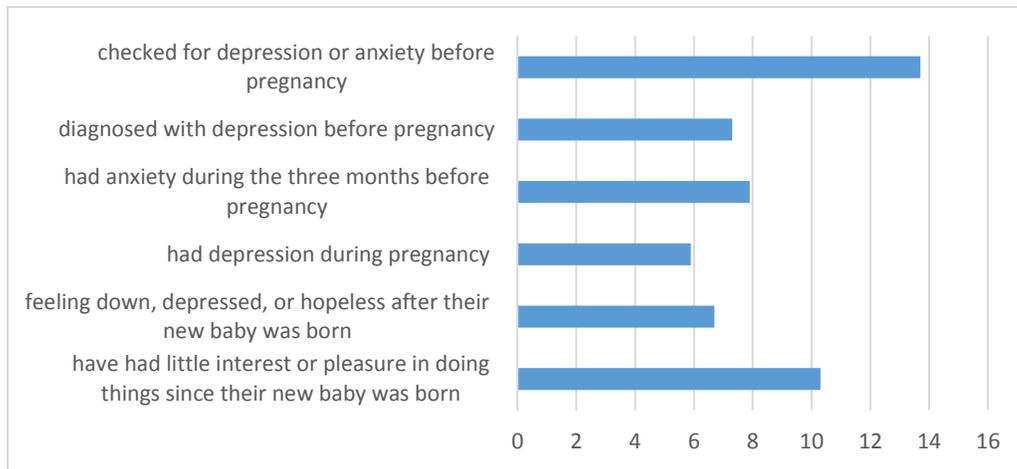


Figure 8. Prevalence (%) of new mothers experiencing mood or anxiety symptoms (Florida PRAMS, 2013)

The **Florida Department of Health**, Division of Public Health Statistics & Performance Management provides epidemiological data in **FLHealthCHARTS**, a Community Health Assessment Resource Tool Set⁵. The CHARTS data are from more than 25 programs and include nearly 3,000 health indicators updated as data are available. These data are summarized according to county as well as state. We were specifically interested in using CHARTS to explore how Alachua County compares to the state of Florida on indices with known association with rates of PMDs.

According to CHARTS data, Alachua County compares favorably to the State of Florida on a number of indices, including the rate of births to unwed mothers (42.1% vs 47.9%), rate of mothers without high school education (9.8% vs 14.2%), the rate of births to teens (8.9% vs 9.5%), and the rate of births covered by Medicaid (43.3% vs 48.8%). Alachua County also has a lower rate of children ages 0-18 are living in households with income below the federal poverty level (FPL) than does the state (22.1% vs 24.0%). On other indices with demonstrated associations with PMDs, Alachua County fares worse than the State of Florida. Alachua County is lower than the State of Florida in rate of prenatal care beginning in the first trimester (78.3% vs 79.8%; Figure 5) and is higher than the state in rates of preterm births (10.3% vs 10.0%) and low birth weight (9.4% vs 8.6%; Figure 6). The county also has higher rates than the state in neonatal (i.e., within 27 days of birth) death (0.7% vs 0.4%) and infant (i.e., within 364 days of birth) death (0.9% vs 0.6%). The rate of domestic violence in Alachua County is also higher than in the State of Florida (595.5 per 100,000 vs 542.1 per 100,000).

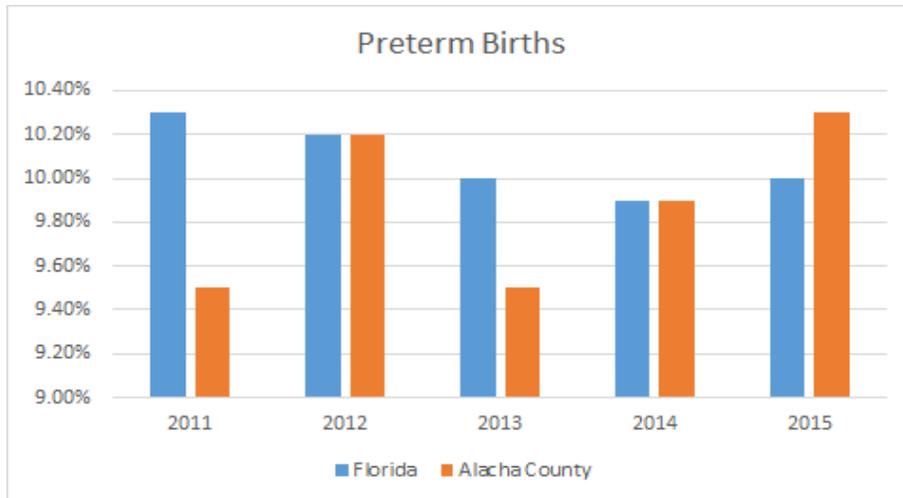


Figure 9. Rates of preterm births (FLHealthCHARTS)

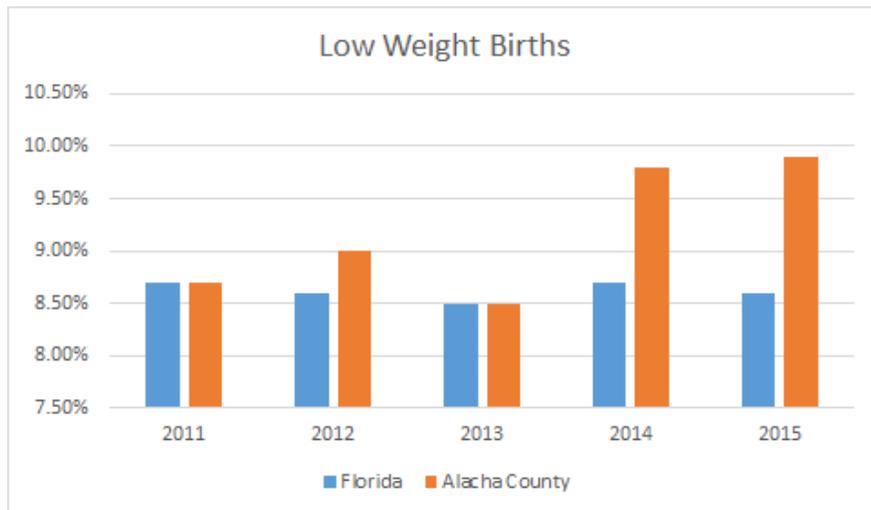


Figure 10. Rates of low weight births (FLHealthCHARTS)

During their 2016 Children’s Services Needs Assessment, WellFlorida conducted focus groups with parents/guardians. One question addressed stressful situations experienced (Figure 7). Among the participants, 28.2% identified problems with delivery of a child and 17.6% indicated that they received mental health services for counseling⁸.

Stressful Situation	% of Parents/Guardians
Experienced financial problems	37.3%
Other medical problems that had to be treated by a doctor	36.8%
Problems with delivery of a child	28.2%
Changes in a close relationship	23.4%
Received mental health services for counseling	17.6%
Experienced changes in your home life	15.5%
Experienced someone trying to hurt or threaten you	7.3%

Source: Question 7, Community Health Survey of Parents/Guardians, 2016. Prepared by: WellFlorida Council, 2016.

Figure 11. Stressful situations reported by parents

SUMMARY

The results of our secondary data search demonstrate that there are limited data available for review other than general demographic data. When compared to the State of Florida, Alachua County fares with mixed results on a number of factors associated with risk of PMDs. However, we do not have the most important type of data for our purposes: rates of PMDs within the county. In addition, this secondary data review did not provide information about maternal mental health resources within the county. Our primary data collection strategy was intended, in part, to address these gaps in available data.

Primary (“local listening”) data

Based on both the epidemiological data available and the workgroup goals recommended by the stakeholders during the Kickoff Meeting for Maternal Mental Health (MMH) Needs Assessment, we developed a plan for collecting local data through a multi-modal “local listening” campaign to learn more about local efforts to promote awareness and reduce MMH stigma, to screen for MMH disorders, to develop processes for referral for appropriate MMH care, to reduce barriers to accessing appropriate care, and to address fragmentation among service and care providers. To obtain a range of perspectives, our data collection plans targeted hospitals, medical practices, individual clinicians, and consumers. In all cases, potential respondents were informed that aggregate results would be included in this report. All collected data was saved in a limited-access shared data folder on an online service (i.e., Google Drive); paper surveys were scanned and saved as PDF files in this drive.

HOSPITAL SURVEY

There are three primary hospitals in Alachua County, including a Veteran’s Administration medical center; a tertiary-care, academic medical center; and a for-profit medical center. We elected to contact just the two hospitals that provide the vast majority of obstetric care in our county: UF Health Shands Hospital and North Florida Regional Medical Center. We contacted

administration of both hospitals, explained the purposes and processes of the community needs assessment, and asked each to complete a survey of practices related to addressing MMH needs of their patients. Both of the hospitals we contacted completed the survey. One of these was completed by the hospital’s Perinatal Education Coordinator. The other was completed by an administrator of the hospital.

To assess the practices of these hospitals, we used 2020 Mom’s standardized *Whole Mom Hospital Survey*, which was developed as a tool for hospitals to assess their own practices or for communities to survey all its birth hospitals. The 19-item survey addresses basic and advanced standards related to staff training; curriculum; policies, procedures, and practices; and programs offered. Hospitals assessing their own practices may complete attestation, submit it to 2020 Mom, and receive a recognition as a “Whole Mom” hospital. In their responses to the survey for this project, neither of our local hospitals reported meeting all of the basic Whole Mom standards.

Table 1 provides a summary of the responses to the *Whole Mom Hospital Survey* by item. In terms of consistency across the two facilities, both reported that they provide an overview of MMH disorders in birth class curriculum, have referral processes in place for accessing inpatient care for severe MMH disorders, assess patient satisfaction with the birth experience, and provide an on-site new parent support group. Neither facility reported that all postpartum care providers (i.e., nurses, lactation consultants, social workers) have received at least three hours of certified training in MMH disorders or that mothers with a NICU stay of at least 48 hours are observed and screened for MMH problems. Both indicated that a maternal depression support group and an inpatient treatment program specific to MMH disorders are under development or “in progress.” For the remaining standards, either the facilities provided different responses or one provided a response and the other marked as “unknown.” Of note, neither facility reported universal screening with the PHQ or EPDS at registration or discharge from the hospital.

Table 1. Response count of two local hospitals to the 2020 Mom *Whole Mom Hospital Survey* (with abbreviated item text)

#	TRAINING	Yes	No	In Progress	N/A or Unknown
1	All postpartum nurses, lactation consultants, and social workers have received a minimum of 3 hours certified training in MMH		2		
2*	Psychiatrist trained in reproductive health disorders is available/on-call	1			1
3*	If a teaching hospital, trains residents, students, or post-docs in MMH	1			1

#	CURRICULUM	Yes	No	In Progress	N/A or Unknown
1	Grand rounds dedicated to MMH at least once per year			1	1
2	Includes an overview of MMH disorders in birth class curriculum	2			

#	POLICIES, PROCEDURES, & PRACTICES	Yes	No	In Progress	N/A or Unknown
1	Promoting and protecting sleep on postpartum floors	1	1		
2	Universal screening with PHQ or EPDS at time of registration. If screen is positive, consult with trained staff.		1		1
3	Materials in discharge packets include MMH	1	1		
4	Universal screening with PHQ or EPDS on postpartum floors or at discharge. If screen is positive, consult with trained staff.		1		1
5	Observation and screening of mothers during NICU stay of longer than 48 hours.		2		
6*	Published MMH telephone line staffed by clinicians trained in MMH.		1		1
7	Referral process in place for accessing inpatient treatment program specific to MMH disorders.	2			
8	Has measurable outcome goals for MMH program(s) in Quality Improvement Program.			1	1
9	Referral process in place to local therapists and psychiatrists.	1			1
10	Assesses patient satisfaction with the birth experience.	2			

#	PROGRAMS	Yes	No	In Progress	N/A or Unknown
1	New parent support group, minimum of 6 weeks, offered on site.	2			
2	Maternal depression support group run by trained staff offered on site or within a 30 mile radius of hospital.			2	
3*	Outpatient day treatment program specific to MMH disorders available through hospital or contracted partner within 30 mile radius.		1	1	
4*	Inpatient treatment program specific to MMH disorders.			2	

*advanced standard

PRACTICE SURVEYS

Although collecting survey data from the local hospitals could provide an overview of practices at large-scale facilities, our workgroup recommendations suggested that variability and coordination of care at the level of direct service providers for pre- and post-natal health care would be another important target for our local listening assessment. Because 2020 Mom provided a template for assessing local MMH services (i.e., the *Local MMH Services Assessment Template*), we elected to use this form as the basis for our survey. The template provided by 2020 Mom is one that was used by the California Task Force on the Status of Maternal Mental Health Care for a statewide survey on MMH. The survey includes items covering services provided, funding sources, and access and barriers to care as well as some open-ended items requesting suggested models for MMH care and general comments or suggestions.

When we examined specific items of the 2020 Mom survey template, we decided that some of the items seemed to be addressing an overall practice pattern of an organization or agency rather than specific practices of an individual service provider. Therefore, we labeled this survey our *Practice Survey* and aimed to collect data from group medical practices and social service agencies. To identify appropriate practices and agencies, we used several methods. First, we did online searches to identify all ob/gyn, midwifery, and pediatrics practices within the county. Second, we brainstormed local social services agencies during our workgroup meetings. Because such agencies are not as easily identified through online search terms, we needed to access the local knowledge of workgroup members to help ensure that we had identified the most appropriate agencies to contact. Finally, the *Practice Survey* retained an item from the 2020 Mom template that asked respondents to identify any related practices or agencies or practices we should contact; it should be noted, however, that we did not identify any additional agencies or practices through this means.

Once we had identified practices and agencies to potentially survey, we assigned each of several workgroup members a list of practices and/or agencies to contact. The workgroup members made initial contact by email, by telephone, or in-person and explained the purposes and processes of the survey and requested participation. If a practice or agency did not specifically decline to participate, the assigned workgroup member followed up with that practice or agency at least one time to request completion of the survey. In addition, general announcements of the ACPMHC via a Facebook group and an email distribution list included reminders of the needs assessment and general requests for completion of surveys.

A Microsoft Access database was developed to record individual responses for each item of the *Practice Survey* for each respondent. The aggregated data was then summarized for the full set of respondents. Although it could be informative to compare response patterns by respondent type (e.g., ob/gyn practice vs pediatric practice vs social service agency), the overall number of responses we received precluded such comparisons. Instead, results are summarized descriptively for the full set of respondents.

Respondents: Through our online searches, we identified 10 local ob/gyn practices, 3 midwifery practices, and 13 pediatric practices. Although we followed best practices for identifying and contacting medical practices, our response rates were low for each type of practice: 30% (3 of 10) of ob/gyn practices, 33% of midwifery practices (1 of 3), and 15% (2 of 13) of pediatric practices; only one practice (a pediatric practice) directly declined to participate. Through our brainstorming and networking, we identified 8 social service agencies that serve mothers and/or babies. Of these, 87.5% (7 of 8), completed surveys. The response rate for surveys of social service agencies was much higher than the response rates for medical practices. Although our overall response rate of 38.2% (13 of 34) is disappointing, we were pleased that at least one practice or organization of each type responded to our request for participation. In addition to having a low response rate, some respondents skipped questions that were not directly applicable to their organization, so the number of responses per item varied.

Services: The survey includes three questions covering services provided by a respondent organization: “How many individuals are served by your organization?” “What is the scope of ALL MATERNAL HEALTH services provided by your organization?” and “What is the scope of MATERNAL MENTAL HEALTH services provided by your organization?” Only eight respondents replied to the first question, and their responses were highly variable, with between 30 and 30,000 individuals being served by the organizations. Tables 2 and 3 summarize rates of endorsement for types of services offered by respondent organizations.

Table 2. Practice survey: Scope of maternal health services provided ($n = 12$)

Service	%	Service	%
Patient education	66.7	Prenatal care	33.3
Family planning services	58.3	Support groups	33.3
Pregnancy / infant health education during prenatal period	58.3	Maternal health advocacy / public policy	33.3
Breastfeeding consultation	58.3	Maternal care training of clinical professionals	25.0
Direct birth / delivery support	41.7	Insurance coverage	16.7
Preconception health management	33.3	Other*	33.3

*Other: “programs, research”; “nutrition education”; “mental health”; “housing for pregnant women and mothers”

Table 3. Practice survey: Scope of maternal mental health services provided (*n* = 13)

Service	%	Service	%
General education & awareness	84.6	MMH advocacy / public policy	15.4
Referrals for MMH treatment / support	69.2	Informal social support	7.7
Screening for MMH disorders	46.2	Insurance coverage for MMH care	7.7
Treatment through licensed therapists	41.7	Formal support groups	0.0
Maternal mental health training of clinical professionals	23.1	Treatment through peer support	0.0
Maintenance of a qualified MMH professional list	15.4	Other*	15.4

*Other: “services are provided through sub-contracted providers”; “Implicit ICT, group prenatal care”

For both maternal health and maternal mental health, the most frequently provided service was education (66.7% and 84.6%, respectively). For maternal health, other frequently (i.e., over 40% of respondents) provided services included other forms of education and consultation (i.e., family planning services, prenatal education, and breastfeeding consultation). For maternal mental health, other frequently (i.e., over 40% of respondents) provided services included MMH screening, referrals, and treatment. The pattern of results for maternal mental health services provided suggest that education, screening, referral, and treatment for MMH problems is available within the community; it must be noted, however, that the set of respondents may not be representative of the full population of organizations within the community.

Funding: Three questions of the survey address funding for maternal mental health services as well as general funding sources: “Does your organization accept insurance for maternal mental health services?” “If you accept insurance, are there barriers to receiving reimbursement from payer and other health plans for maternal mental health services?” and “What additional funding sources does your organization rely on?” Of the 11 respondents who answered the first of these questions, 8 indicated that they do not accept insurance for maternal mental health services. Two of these respondents indicated that they did not because their programs were grant-funded. The other six provided “other” reasons: “not clinical,” “NA - no direct service provisions,” “we provide housing, we receive grants & some is self-pay,” “we do not charge for services,” “We refer out for MMH, out of our scope. Our insurance contracts do not include MMH services in our offices.” and “we see the children.” Of the 10 respondents who replied to the question regarding barriers to reimbursement, 6 indicated that they accepted no insurance and 2 experienced no barriers to reimbursement. The remaining 2 respondents identified the following as barriers to reimbursement: “Limited / no reimbursement from Medicaid for ‘social support’ and non-psychiatric related perinatal depression services,” “Limited number of visits allowed for services from public and commercial insurance providers,

which might not adequately treat perinatal depression,” and “Not all patients have mental health benefits.”

A total of 7 respondents provided an answer to the question regarding sources of general funding. One respondent identified private donors and one identified state funding as a single source of funding. The remaining 5 respondents identified some combination of local jurisdiction funding, state funding, federal grants, private grants, and private donors (see Table 4).

Table 4. Practice survey: sources of funding ($n = 7$; could select more than one option)

Option	Number	Percent
Local jurisdictional funding	1	14.3
State funding	5	71.4
Federal grants	4	57.1
Private grants	2	28.6
Private donors	4	57.1

Access and Barriers to Care: The survey included eight items assessing access and barriers to care. The first of these asks, “Do you believe that access to maternal mental health services is a problem in our community?” Of the 12 respondents, all except 1 responded “yes” to this item (11 of 12; 91.7%), indicating a perception of poor access to MMH care. The next item includes a list of 17 potential barriers contributing to MMH problems in our community. Respondents were asked to rate each potential barrier on a scale of 1 (“not a problem”) to 5 (“extremely problematic”) or to mark “0” for “I don’t know.” Table 5 presents the mean rating for each of the items ordered from most to least problematic; responses of “0” (“I don’t know”) were not included in the means.

Table 5. Practice survey: mean respondent ratings* of barriers to MMH care in our community

Barrier	mean
Lack of insurance coverage	4.10
Lack of income to pay for therapy	4.09
Doctors / other practitioners will not accept Medicaid	4.00
Lack of understanding of insurance scope and benefits	4.00
Lack of income to pay for medical emergencies	3.86
Lack of transportation	3.70
Long waiting lists	3.60
Lack of practitioners with expertise in perinatal depression	3.57
Lack of income to pay for prescriptions	3.50
Lack of therapists that accept insurance for therapy	3.17
Limited hours of operation for accessing clinical services	3.00
Lack of educational resources for maternal mental health providers	3.00
Screening providers do not know where to make treatment referrals	2.83
Limited or no programming / treatment options to accommodate perinatal depression	2.75
Lack of regular screenings by physicians	2.71
Lack of social support opportunities or support groups	2.60
No clinics or doctor offices nearby – must travel to access services	2.43

*range = 1 (“not a problem”) to 5 (“extremely problematic”)

Of the 17 potential barriers, the 5 with the highest ratings among respondents addressed deficits in insurance or income; 2 additional income or insurance related items were in the top 10 most highly rated items. The remaining items did not follow a clear pattern in terms of types of potential barriers being rated similarly. Respondents were also asked a free-response question concerning barriers: “Please describe any other barriers contributing to maternal mental health care access in our community.” The responses to this question are listed in Table 6. Several respondents referred to issues of insurance coverage and transportation, both of which were also listed in the prior question. In addition, several respondents referred to stigma and low consumer awareness of services available to address MMH concerns.

Table 6. Practice survey: respondent-provided “other barriers contributing to maternal mental health care access in our community”

Response
I don't think consumers know what services are out there and available to them unless their care provider can connect them to those resources.
Limited therapy benefits on private health insurance plans
Our families often rely on Medicaid or state funding to help them access services. There are a limited number of providers with perinatal expertise and it often comes down to our agency having to fund these services directly, as the providers do not accept Medicaid plans. Transportation is often a barrier for the population we serve.

Consumer education / knowledge of options; availability of enough practitioners to client ratio; stigma; & transportation
Just starting our pediatric practice. In our experience thus far there have been no problems with access and recognition.
transportation
Stigma & shame of mental health issues seems to be the biggest issue I encounter. Also, lack of understanding of what things are available.
Women are often unfamiliar with what they are feeling - if it is normal or not and do not reach out as quickly as they should. More educational materials would help.

In addition to rating barriers to accessing MMH services, respondents were asked to identify barriers to making referrals for MMH services. Although the question was worded as follows, “Are there barriers to making referrals for maternal mental health services in our community? If yes, please indicate and check all that apply:” there was not a response option for “no”; instead, the response options listed potential barriers. It is possible that the 3 respondents who did not answer this question believed there were no barriers to making referrals for MMH care. The remaining respondents each selected at least one barrier, as summarized in Table 7. Overall, respondents did not seem to view low professional awareness or procedures as of most concern (with 40 and 30% endorsement, respectively). The respondents unanimously identified low public awareness of MMH needs and services as a barrier to referral.

Table 7. Practice survey: barriers to making referrals for MMH services (*n* = 10; respondents could select more than one option)

Option	Number	Percent
Lack of professional awareness of perinatal depression detection, screening, and referral among clinical, educational, and social service agencies, or other points of contact for pregnant and postpartum women	4	40.0
Insufficient processes for clinical providers to recognize, screen, and refer to perinatal depression services	3	30.0
Perinatal depression resources or referral process are not known by clinicians or social service professionals	5	50.0
Limited cross-collaboration with other medical and social services regarding perinatal depression screening, referrals, and treatment	6	60.0
Low public awareness of maternal mental health needs and available services	10	100.0

With regard to providing MMH treatment, respondents were asked, “Is your organization able to provide treatment to individuals seeking / being referred for maternal mental health care in

a timely manner?” Of the 13 respondents, 8 selected the option indicating that they do not provide treatment services (one of these selected “other” and indicated that they do not provide services). Of the remaining 5 respondents, 3 indicated that they provide treatment within two weeks and 2 indicated that they provide treatment within one month. In response to the question, “Is there a population your organization is not able to serve that frequently requests mental health services?” 2 respondents omitted a response, 10 replied “no,” and 1 replied “yes”: this respondent indicated that “Medicaid patients” request services but are unable to be treated through that organization. In response to the question, “To your knowledge, are there any reproductive psychiatrists in the region?” 1 omitted a reply, 10 replied “no,” and 2 replied “yes” and named the same reproductive psychiatrist.

For the final question of the Access and Barriers section of the survey, respondents were asked the following free-response question: “In your opinion, what would make the biggest difference in improving maternal mental health care in Alachua County?” The 9 responses to this question are listed in Table 8.

Table 8. Practice survey: what would make biggest difference in improving MMH care in our county?

Response
Raising more awareness. Training/educational opportunities for care providers that work with pregnant women.
greater access to a competent provider network that is able to accept Medicaid managed plans. Providers with specializations often do not accept Medicaid plans.
Creating more awareness around the screening process and educating providers on social services available w/in our community. Within our program, we are constantly trying to educate the community on the services we provide but there are still so many who don't know about us.
Comprehensive, preventative healthcare. Pediatric practices using Implicit at well-baby visits.
better funding
As we grow, a central referral agency for those not served by a primary/psych provider
Providers who can evaluate/treat Medicaid pts
Funds for bus passes/ transportation or mental health professionals coming to different locations to assist mother so they do not have to travel
Educational and referral materials to those providing services to pregnant women and moms and dads. Brochures, business cards, posters about postpartum spectrum would be wonderful!

The final section of the survey was a Conclusion section, in which respondents were asked to identify any models of MMH coordination of care, screening, or treatment; other organizations

they believe we should contact; interest in participating in a follow-up interview; and interest in joining the ACPMHC. Only two other organizations were suggested and two models (both of which were familiar to the coalition team). The final question asked respondents to “share any additional comments, questions, or suggestions for the project team.” No respondent added additional comments in response to this prompt.

INDIVIDUAL PROVIDER SURVEYS

Although the *Practice Surveys* addressed some details of individual provider practice patterns, it did not include questions concerning screening and referral for MMH care. Therefore, we added a page to the end of the *Practice Survey* with a brief survey to be completed by one individual care provider associated with a medical practice; we identified this as the *Individual Provider Survey*. This survey consists of two primary questions (i.e., “Do you routinely screen for maternal mental health problems?” and “If you do identify a maternal mental health problem, what do you do to address it?”) with brief sub-questions based on primary question responses. Although our intent was to have one provider from each medical practice complete an *Individual Provider Survey*, we received additional individual provider responses through either directly recruiting members of the ACPMHC to complete the questions or receiving responses from more than one provider at a given medical practice. This convenience sample was not intended to be representative of all maternal or pediatric medical care providers in the county; instead, it was intended to provide supplemental information specific to our project goals from the surveyed medical practices.

The *Individual Provider Survey* was completed by 15 respondents, including 9 who care primarily for mothers (i.e., 2 medical doctors and 2 registered nurses from obstetrics practices and 2 midwives,) and 6 who care primarily for babies (i.e., 5 medical doctors and 1 advanced registered nurse practitioner from pediatric practices). All of the 15 respondents reported that they routinely screen for MMH problems. The majority of these (i.e., 80%) reported that they screen at more than one predetermined time; no respondent reported screening at only one predetermined time (Table 9). In response to the question, “Do you use a standardized measure to screen for maternal mental health problems?” 2 providers (13.3%) gave no response, 3 providers (20.0%) replied “no,” and 10 providers (66.7%) replied “yes”; all of these identified either the EPDS or the EPDS and PHQ-9 as the screening measure(s) they use.

Table 9. MMH screening patterns among individual medical providers ($n = 15$)

Option	Number	Percent
Screen at one predetermined time	0	0
Screen at more than one predetermined time	12	80.0
Screen at all perinatal visits	1	6.7
Screen only if there is an indication of a problem	2	13.3

The second primary question of the *Individual Provider Survey* was, “If you DO identify a maternal mental health problem (either through routine screening or any other means), what do you do to address it?” Respondents could select as many options as applied to them from among three preset responses and “other.” One respondent provided no response to this question. Table 10 summarizes the practice pattern of respondents based on this question.

Table 10. Individual medical providers’ patterns of addressing MMH problems ($n = 14$)

Option	Number	Percent
Prescribe psychotropic medication myself	5	35.7
Refer to a psychiatrist for medication management	5	35.7
Refer to other mental health provider (e.g., psychologist, mental health counselor, clinical social worker) for psychotherapy	11	78.6
Other	4	28.6

The options addressing referral to a psychiatrist or other mental health professional included sub-questions asking respondents if they referred to a specific provider. Although none marked “yes” for referring to a specific psychiatrist, 1 respondent did name a psychiatrist. Of the 11 who reported that they refer to another mental health provider, 7 named a specific MMH care provider and 2 named a specific social service agency. For both of these sub-questions, there was one response (by different respondents) that indicated that a referral would be based at least partially on insurance coverage. The 4 “other” responses were as follows: “recommend support groups”; “[two named local inpatient psychiatric facilities] if crisis”; “refer to MD for management - referral for counseling, prescriptions, inpatient counseling if needed”; and “refer back to OB.”

FOCUS GROUPS

Our initial plan included collecting qualitative data from consumers (i.e., parents) and individual providers through focus groups. When conducting a needs assessment, there are two main approaches when approaching participants to participate: an indirect and a direct approach. An indirect approach relies on the support, endorsement or direct involvement of intermediaries. A direct approach involves contacting prospective participants directly (e.g., direct mail, radio, flyers, and posters). A direct approach was used to obtain participants for our focus group, specifically using flyers. Our public health intern and one other ACPMHC member researched focus group methodology and developed a list of questions to ask to each of these groups. They identified times and locations for the groups and posted flyers in a variety of locations, including offices of medical providers, library bulletin boards, coffee shops, the local university and college, and local businesses. Unfortunately, only two consumers and no providers responded to the advertisements with an intention to attend, so these focus groups were cancelled. We believe one reason for such a low response rate was timing: the advertisements were posted a relatively short time before the focus groups were set to occur.

Because we were aiming to follow a relatively tight timeline set by 2020 Mom, we did not have an opportunity to start over and reschedule the focus groups. Instead, we conducted one small focus group with a convenience sample of seven women who attended a monthly support group at the office of one of the workgroup members. In addition, we developed a survey to obtain data from consumers (described below).

The focus group was comprised of 7 women, all of whom gave birth and received their pre- and postnatal care in Alachua County. Of the 7 women, 3 had more than one child, 1 was currently pregnant, and 5 were currently married. The findings highlighted two main themes, barriers and needs, and several categories within those themes. One category that emerged from the barrier theme during the focus group was a lack of visibility and awareness that emotional/mental health is a “thing” to consider during perinatal/reproductive years. Another barrier discussed was a lack of information regarding resources available and risk factors for perinatal mood disorders. The participants discussed a lack of screening for MMH problems; if a screening did occur, there was a lack of follow-up. Focus on the baby rather than the mother contributed to another perceived barrier. All of the women also mentioned that their relationships with their spouses/significant others had suffered, so the women experienced isolation. Five of the women reported that they perceived their birth to be a traumatic experience.

The other theme, needs, produced several categories as well. The women suggested there should be more visible information in doctors’ offices (including primary care, OBGYN, pediatrics) about perinatal mood disorders, support groups, and risk factors. They also suggested more conversation and screenings for perinatal mood disorders. Lastly, they suggested more prenatal education on emotional health/relationship health. The findings from this focus group highlighted barriers as well as suggestions on how to address these barriers. These findings suggest that more information about perinatal mood disorders, risk factors, and resources available could be of benefit to both consumers and their providers.

CONSUMER SURVEY

As noted above, our *Consumer Survey* was developed as a means to collect data from consumers (i.e., mothers and fathers) after our planned community focus groups were cancelled for a low response rate. We elected to include some of the planned focus group questions in the survey and to add questions based on well-documented areas of concern related to MMH (e.g., stigma). In addition, we included questions addressing demographic characteristics of the survey respondents. Questions were in multiple formats, including yes/no, multiple choice, and free response. The survey was developed and shared using an on-line platform that allowed respondents to link to the survey anonymously; data was archived through a limited-access Google Drive. Respondents were recruited through the existing online communication methods of the ACPMHC, including an electronic mailing list and a Facebook group for community members interested in MMH concerns.

After the survey was closed to new responses, the data set was screened for irregularities. There were several cases of repeat submissions in which all data were exactly the same, including long responses to free-response questions. It was theorized that these duplicated cases resulted from the same survey being submitted more than once rather than the same respondent answering all questions more than once. The duplicated rows of data were deleted in the final data set. Although this self-selected convenience sample cannot be viewed as representative of the population of interest, this data collection method allowed us to include findings from key stakeholders.

Table 11 summarizes the demographic characteristics of survey respondents. The respondents were primarily Alachua County residents (89.9%), women (94.9%), White/Caucasian (78.5%), married (78.5%), and well educated (40.5% college grad, 40.5% post grad). The majority of respondents were in the 30-49 year old age range (72.2%). In terms of employment, 59.7% of respondents were working full-time, 10.1% were working part-time, and 21.5% were stay at home parents. Although the sample's demographic breakdown is not representative of the county population, it does include some variability in respondents.

Table 11. Demographic characteristics of Consumer Survey respondents (*N* = 79)

Domain	Response option	number	percent
Alachua County resident	Yes	71	89.9
	No	8	10.1
Sex	Woman	75	94.9
	Man	4	5.1
Age group	18-29 year old	18	22.8
	30-49 year old	57	72.2
	50-64 year old	4	5.1
Race / ethnicity	White / Caucasian	62	78.5
	Black / African-American	8	10.1
	Hispanic / Latino	2	2.5
	Asian	4	5.1
	Prefer not to say	3	3.8
Relationship status	Married	62	78.5
	Living with significant other	8	10.1
	Single, not married	6	7.6
	Divorced	3	3.8
Highest education	High school grad or less	2	2.5
	Technical/trade school	4	5.1
	Some college	9	11.4
	College grad	32	40.5
	Post graduate	32	40.5
Current employment	Full-time employment	46	59.7
	Part-time employment	8	10.1

Domain	Response option	number	percent
	Business owner / self-employed	2	2.5
	On leave	4	5.1
	Stay at home parent	17	21.5
	Student	1	1.3
	Disabled	1	1.3

Table 12 summarizes the obstetric or parenting characteristics of the respondents to the consumer survey. Of note, a male respondent could answer some of these questions referring to his partner but not for himself because they pertain specifically to pregnancy or birth.

Overall, the majority of respondents (91.1%) indicated that they receive ob/gyn care in Alachua County and 84.8% have given birth in Alachua County. The number of pregnancies respondents reported ranged from 1 to 11 ($M = 3.8$, $SD = 2.2$), and the number of children reported ranged from 0 to 4 ($M = 1.7$, $SD = 1.0$). With regard to prenatal care, 94.9% indicated that they received prenatal care during pregnancy, with prenatal care beginning at about week 8 (range: week 0 to week 38; $M = 7.8$, $SD = 7.3$). The question asking about the type of professional who provided prenatal care for respondents allowed the respondents to identify more than one response, and a number of respondents identified more than type of prenatal care provider. The most common source of prenatal care was from an ob/gyn physician (84.8%); 27.8% received care from a certified nurse midwife and another 10.1% from a traditional midwife. In terms of time since last birth, respondents were relatively evenly divided among within 1 year (34.2%), 1-3 years (31.6%), and 3 or more years (34.2%). When asked if they had experienced fertility challenges or infertility, 13.9% responded “yes.” A total of 29.1% had experienced perinatal loss, including miscarriage, stillbirth, or infant loss. Of the 23 who had experienced a loss, the average number of losses was 1.9 ($SD = 2.1$; range: 1-10), and the average time since the loss was 6.6 years ($SD = 8.3$; range: 1-37).

Table 12. Obstetric / parenting characteristics of Consumer Survey respondents ($N = 79$)

Domain	Response option	number	percent	Mean	SD
Receive ob/gyn care in Alachua Co.	No	7	8.9		
	Yes	72	91.1		
Have given birth in Alachua Co.	No	12	15.2		
	Yes	67	84.8		
Currently pregnant	No	70	88.6		
	Maybe	1	1.3		
	Yes	8	10.1		
Number of pregnancies	(range: 1-11)			3.8	2.2
Number of children	(range: 0-4)			1.7	1.0

Domain	Response option	number	percent	Mean	SD
Received prenatal care (if ever pregnant)	No	4	5.1		
	Yes	75	94.9		
Prenatal care starting week:	<i>(range: 0-38)</i>			7.8	7.3
Source of prenatal care	N/A or did not	2	2.6		
	OB/GYN	67	84.8		
	Certified nurse midwife	22	27.8		
	Midwife, traditional	8	10.1		
Time since last birth	0-3 months	5	6.3		
	4-8 months	11	13.9		
	9-12 months	11	13.9		
	1-3 years	25	31.6		
	3+ years	27	34.2		
Experienced fertility challenges / infertility	No	68	86.1		
	Yes	11	13.9		
Experienced miscarriage, stillbirth, infant loss	No	56	70.9		
	Yes	23	29.1		
If loss, how many?	<i>(range: 1-10)</i>			1.9	2.1
If loss, years since last loss?	<i>(range: 1-37)</i>			6.6	8.3
If loss, support received?	No	18	78.3		
	Yes	5	21.7		

As noted above, the *Consumer Survey* included not only yes/no and multiple-choice questions but also free-response questions. One of these was the broad question, “What does health mean to you?” Themes from the responses to this question included physical, emotional, and spiritual well-being, and multiple respondents identified all three of these factors. When asked to describe “What is a healthy pregnancy?” responses included three themes: no complications (i.e., full term), healthy mother and baby, and eating well/exercising.

When asked “If you have been pregnant, would you consider it a healthy pregnancy?” 83.5% responded “yes,” 8.9% responded “no,” and 7.6% provided a mixed response. Most of these respondents had experienced more than one pregnancy and noted that they would respond differently for the different pregnancies. Figures 8 and 9 summarize education or information respondents received about pregnancy. Almost all respondents (94.9%) received some form of education about pregnancy, and at least some received education about each of the topic areas presented, with the most common topics of their prenatal education being giving birth (88.6%), feeding and caring for baby (86.1%), and nutrition/exercise (82.3%).

Figure 12.

Did you receive any education or information about pregnancy?

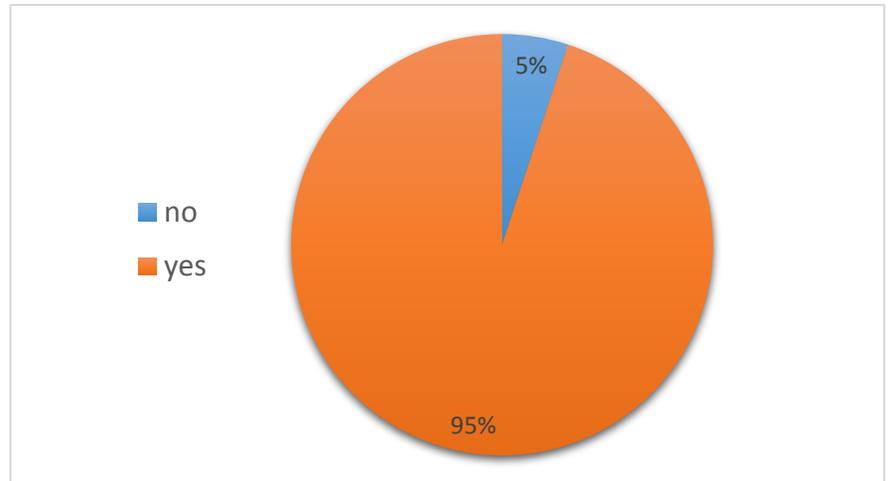
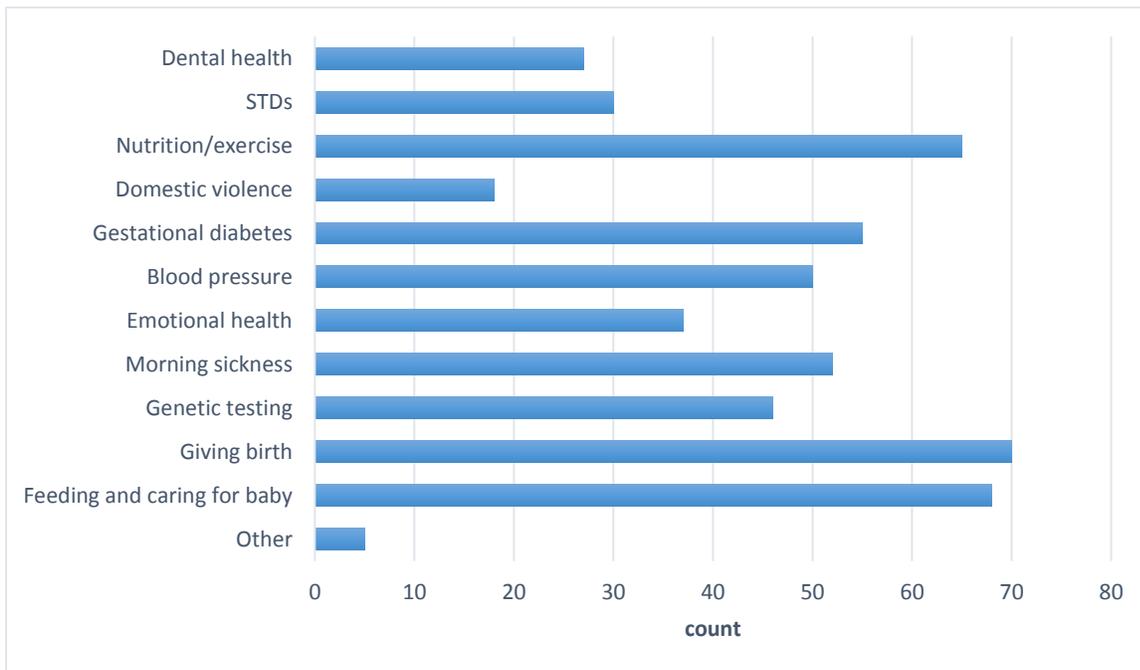
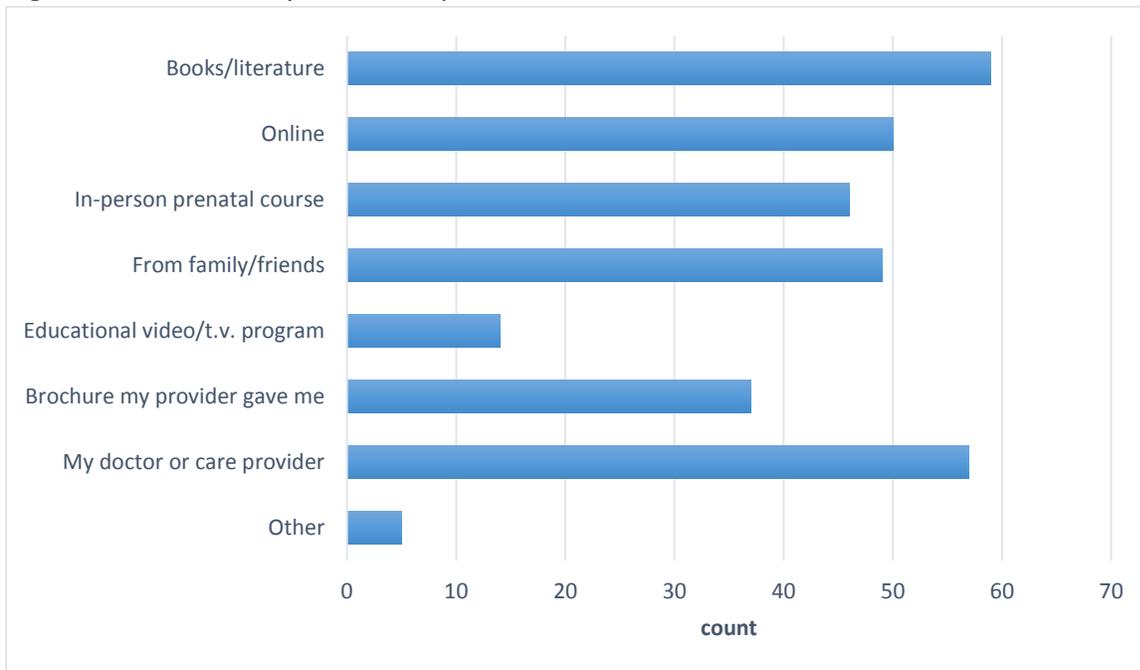


Figure 13. If yes, what were you educated about?



Respondents identified a number of sources of prenatal information, with the most common sources being books (74.7%) and a medical provider (72.2%; Figure 10).

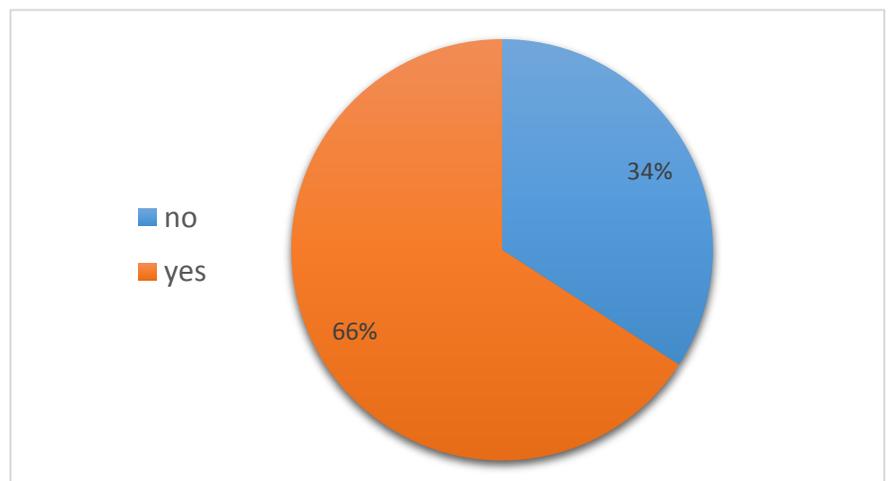
Figure 14. Where did you receive prenatal education?



When asked if they had received information or education about emotional or mental health during or after pregnancy, 65.8% responded affirmatively (Figure 11). This is higher than the proportion in the prior question, which listed “emotional health” as one of the potential topics of prenatal education (46.8%). The most common source of this information was a medical provider (55.7%), but a number of other sources were also endorsed (see Figure 12). Of note, although books/literature was cited as a source of prenatal education by 75%, books/t.v./videos was cited as a source of education about perinatal emotional/mental health by only 16.5%, suggesting that more of the education about MMH was in-person.

Figure 15.

Have you ever received education on emotional/mental health during or after pregnancy?



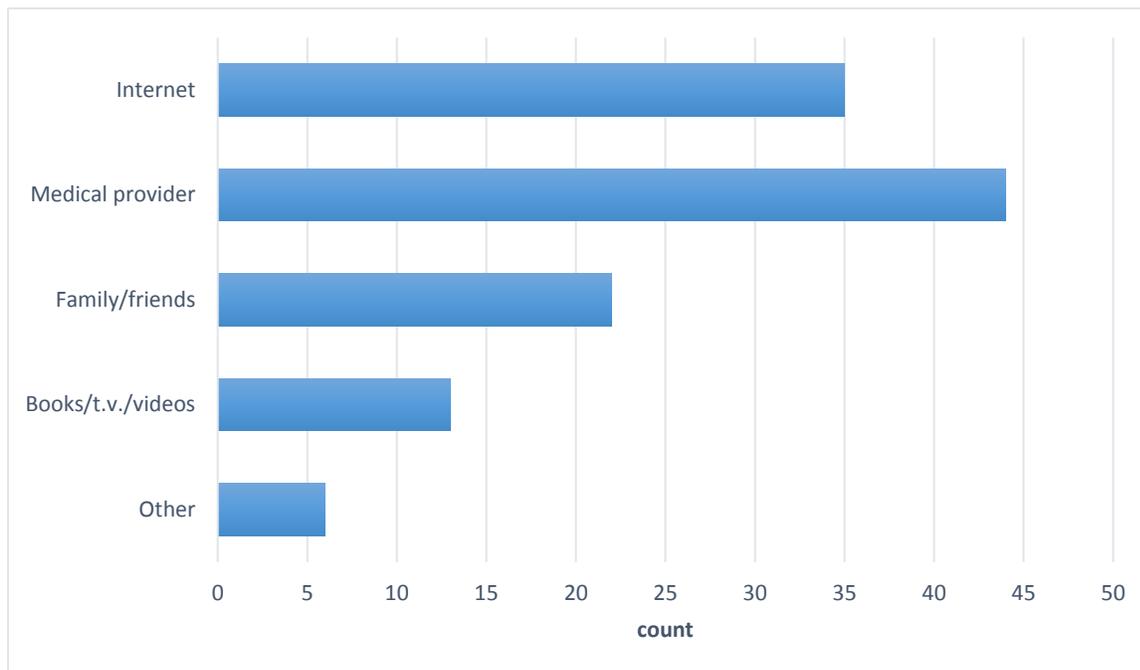


Figure 16. If yes, where did you receive this education? (on emotional/mental health during or after pregnancy)

Participants were next asked to provide free-response descriptions of the most and least helpful aspects of the education they received on emotional or mental health. These responses were then reviewed for common themes. Responses to the question, “What was most helpful about the education on emotional/mental health that you received?” produced three themes, all of which pertained to increased knowledge: it is normal to have these feelings, resources are available (e.g., information, support groups), and there are ways to handle the signs. There were relatively few responses to the question, “Was there anything least helpful or supportive?” and the responses produced one theme: limited follow-up from medical care providers.

In terms of being screened for potential MMH issues, the majority of respondents (74.7%) recalled being asked about emotional or mental health in the perinatal period (Figure 13), with the most frequent source of questioning being a medical provider (Figure 14).

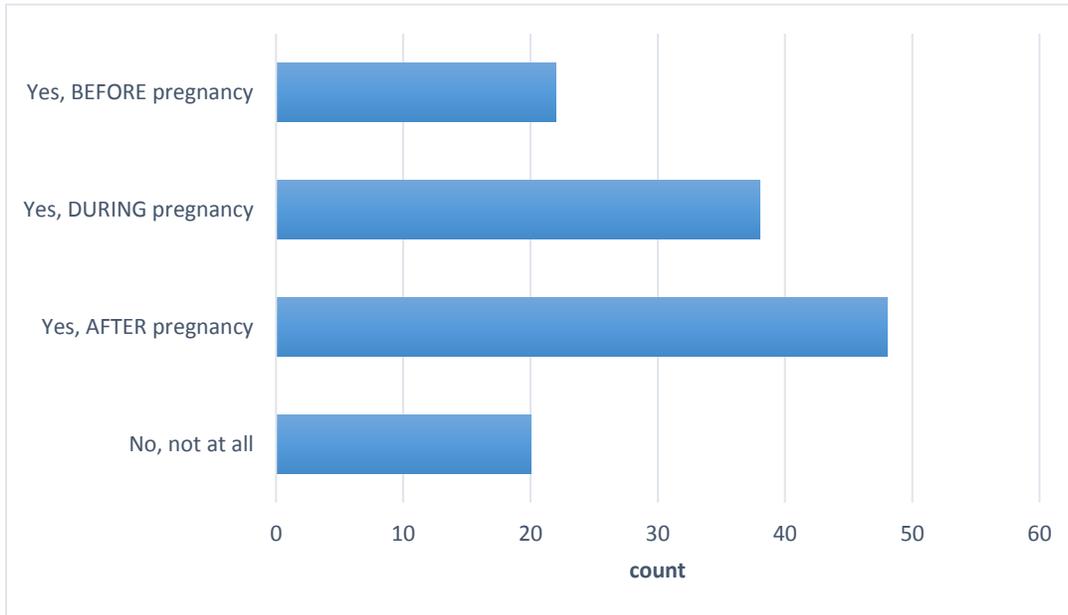


Figure 17. Do you remember being ASKED questions about your past or current emotional/mental health before, during OR after pregnancy?

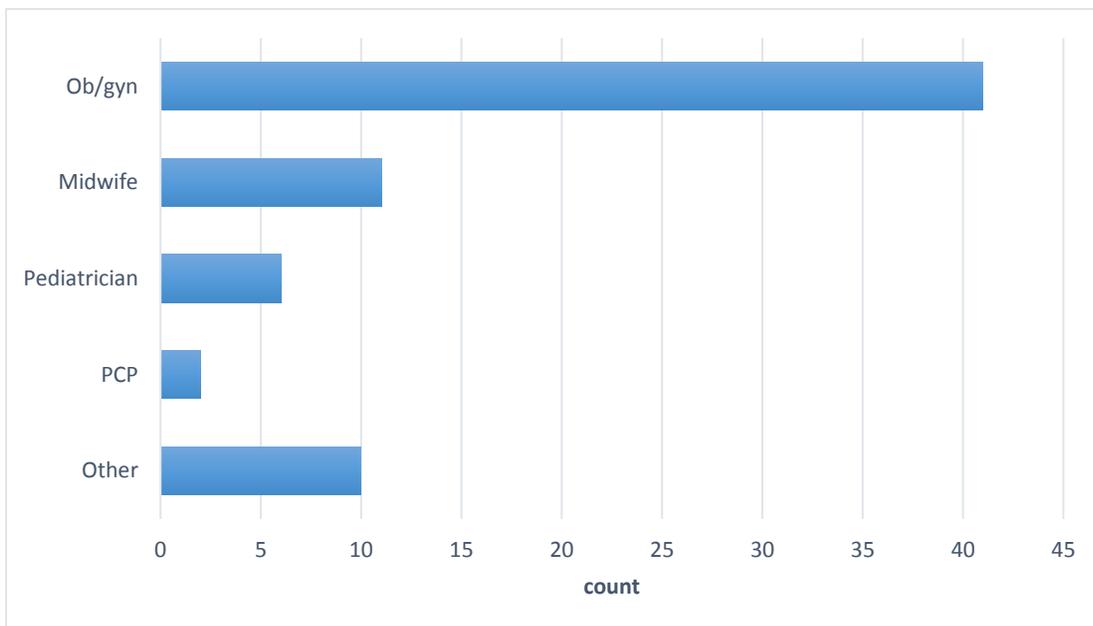


Figure 18. If yes, who asked you?

The majority of respondents (86.1%) described feeling comfortable talking with a medical provider about emotional or mental health (Figure 15). The reasons for not feeling comfortable discussing this topic with a provider included difficulty describing feelings (7.6%), fear/stigma or

embarrassment (each 6.3%), limited trust in provider (3.8%), and other reasons (7.6%), most of which overlapped with the listed options.

Figure 19.

Do you feel comfortable talking with your doctor, midwife or other medical provider about your emotional/mental health?

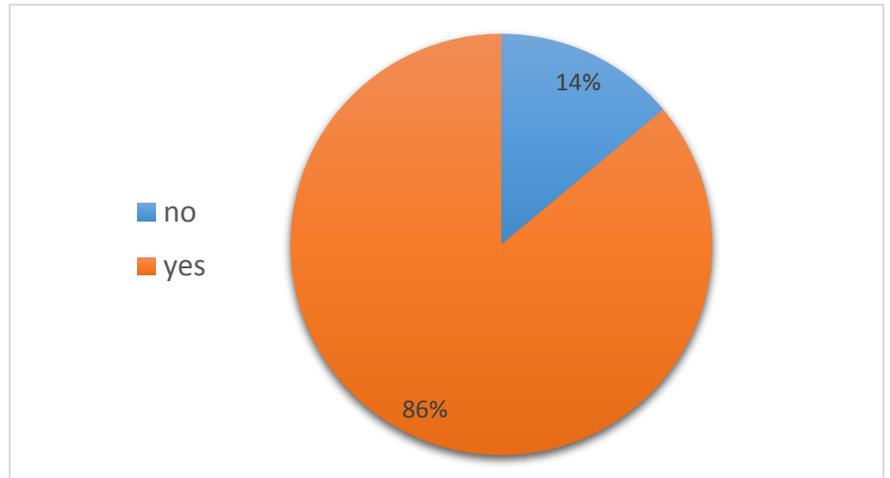
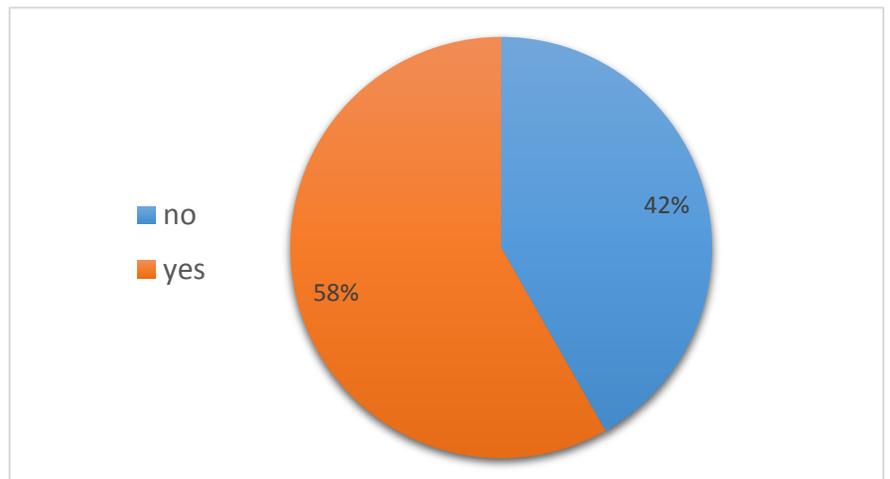


Figure 20.

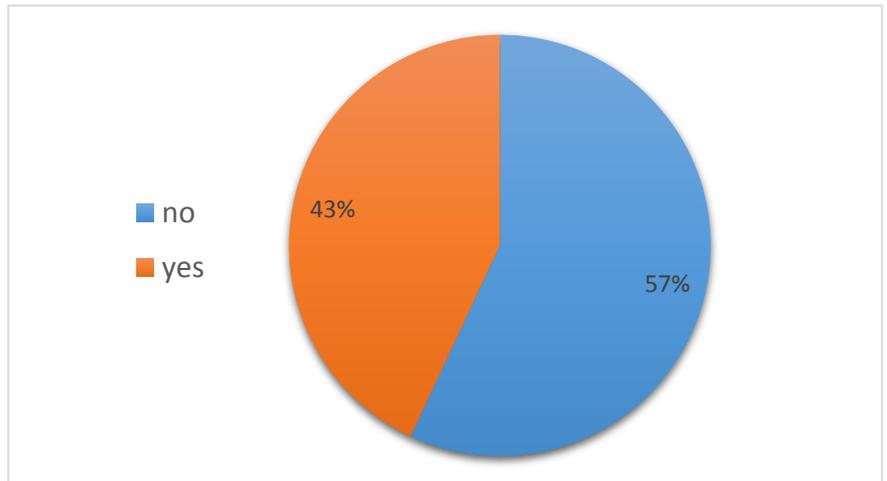
Have you been given a written questionnaire about emotional/mental health during or after pregnancy by any medical provider?



More than half of the respondents (58.2%) recalled receiving a written questionnaire concerning MMH, and the majority (88.6%) indicated that they would be likely to respond to such a questionnaire honestly (Figures 16 and 17). Among the respondents who recalled being given a questionnaire addressing MMH, 26.1% indicated that “nothing” happened after administration of the questionnaire and 54.3% recalled discussing results with a provider.

Figure 21.

If yes, were you likely to answer honestly?



Less than half of the respondents (43.0%) recalled being asked about their emotional health by their child's pediatrician, although the majority indicated that the pediatrician's office would be an acceptable source of MMH information (Figures 18 and 19).

Figure 22.

Has your child's pediatrician ever asked about your emotional health?

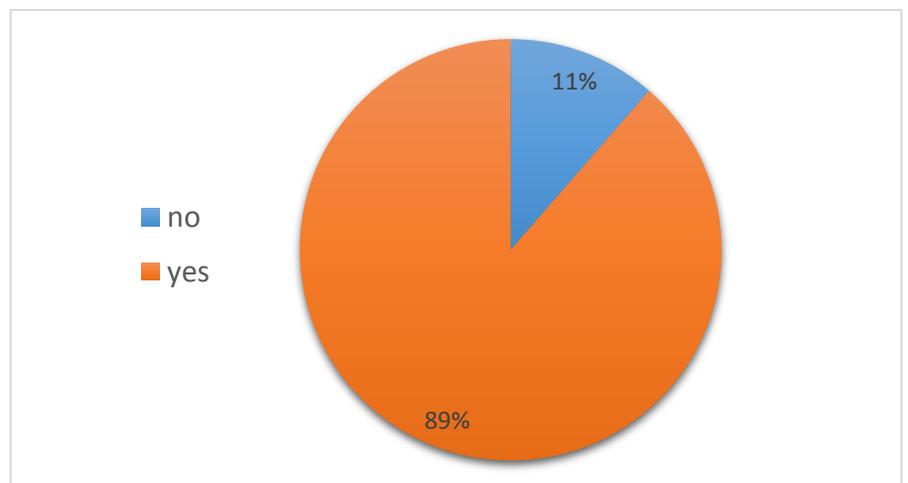
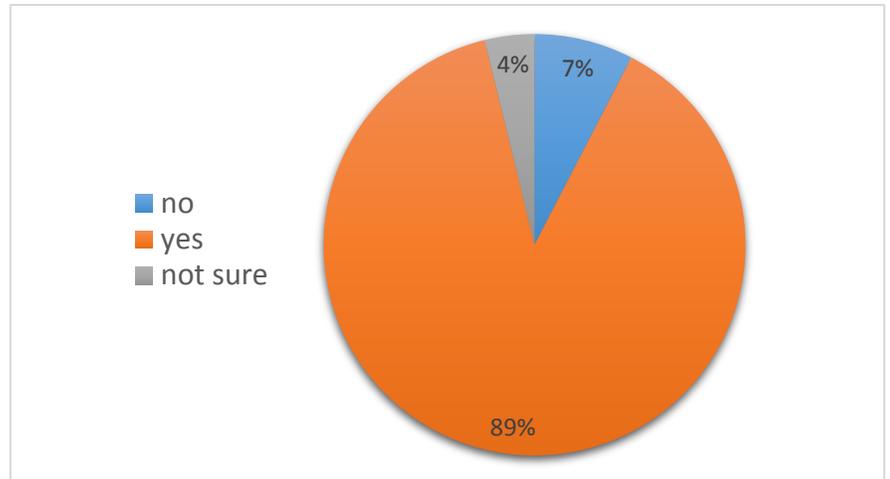


Figure 23.

Would the pediatrician's office be an acceptable place for receiving information on emotional health resources for parents?



When asked about potential sources of support for emotional health complications in the perinatal period, the most common source of support was family and friends (73.4%), followed by a medical provider and mental health professional (59.5% and 55.7%, respectively; see Figure 20). Although more than half indicated that they would seek support from a mental health therapist if needed, 27.8% indicated that they would not know how to find a mental health specialist. Themes from a free-response question regarding how a respondent would find a mental health specialist included seeking a referral from a medical provider, reviewing a provider list of an insurance company, and seeking online information.

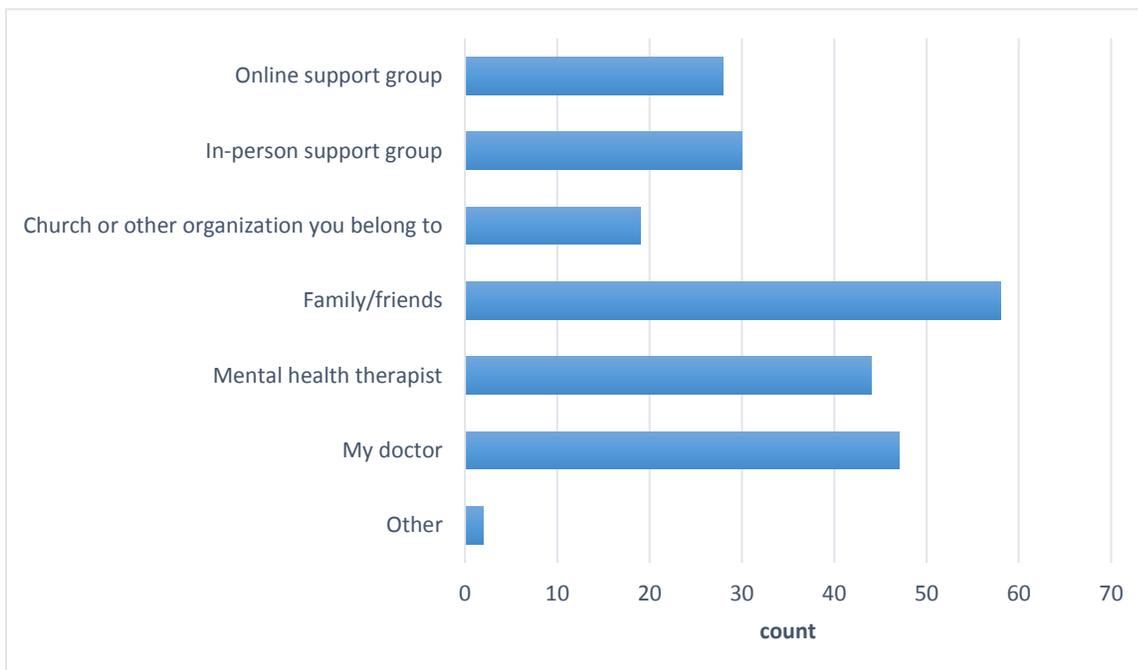


Figure 24. Where would you seek support if you were experiencing emotional health complications during pregnancy or after?

When respondents were asked if they had experienced emotional or mental health problems related to infertility, loss, or in the perinatal period, 35.4% answered affirmatively and another 7.6% were unsure (Figure 21). A total of 3 respondents (3.8%) answered “yes” to the question, “Have you ever gone to the emergency room for emotional health/mental health complications?” (Figure 22). Of note, this question did not specifically address emergent care for emotional or mental health problems during the perinatal period.

Figure 25.

Have you experienced emotional health complications related to infertility, loss, during pregnancy or after the birth of your baby?

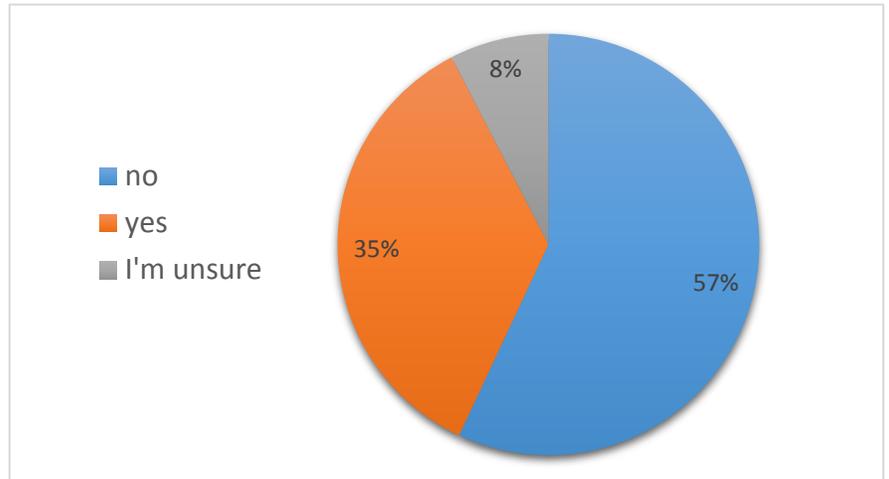
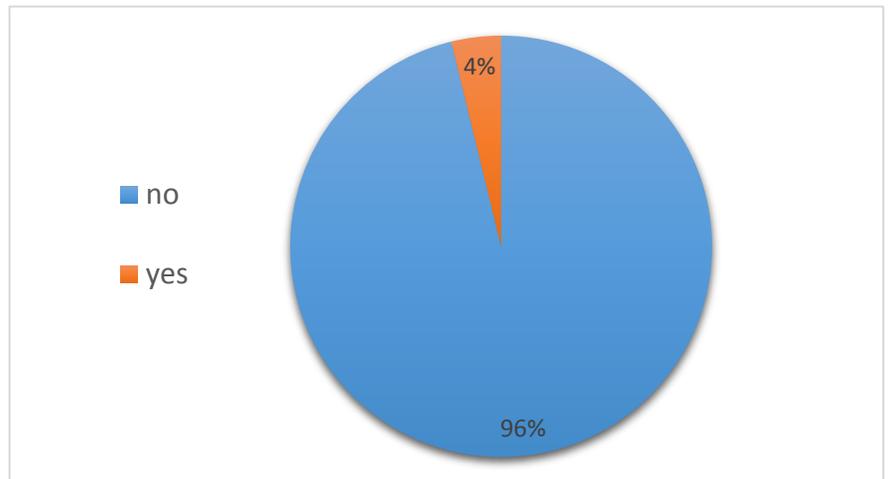


Figure 26.

Have you ever gone to the emergency room for emotional health/mental health complications?



Respondents were almost evenly divided between “yes” and “I’m unsure” in response to the question, “Are there mental health providers in Alachua County for infertility, loss, pregnancy or after birth?” (49.4% and 50.6%, respectively). No respondents indicated “no” in response to this question. In a related question, respondents were asked “Are there any resources Alachua County does not have related to infertility, loss, pregnancy and new parenthood?” Although this was a free-response question, the responses could be easily categorized. The majority of

respondents (67.1%) indicated that they did not know or were unsure, 16.5% responded no, and 15.2% responded yes; of this last group, 3 recommended more new parent support groups, 3 recommended more information at doctors' offices about MMH issues and trained MMH providers, 2 recommended information about high-risk pregnancy and/or pregnancy loss, 1 recommended a "doula co-op," 1 recommended an inpatient unit for MMH problems, 1 recommended more staff training in a hospital, and 1 commented on limited resources for the un- or under-insured.

Respondents were also asked, "Are any of the following a barrier for you to get emotional/mental health care for fertility, loss, pregnancy or postpartum?" (Figure 23). Although only 2 respondents (2.5%) selected the option "no barriers for me," 33 respondents (41.8%) omitted an answer to this question, suggesting no barriers for 35 of the 79 respondents (44.3%). The next two most common responses to this question were financial: cost of services (39.2%) and insurance limitations (20.3%).

Notably, no respondent selected lack of transportation as a barrier to accessing mental health care, which is in contrast to the pattern of data from providers. The two potential explanations for this discrepancy are that the providers are assuming more difficulty with transportation than consumers are experiencing or that the sample of respondents to the *Consumer Survey* is not representative of the local population. Given the demographic make-up of this self-selected sample, it is likely that the latter is the most parsimonious explanation.

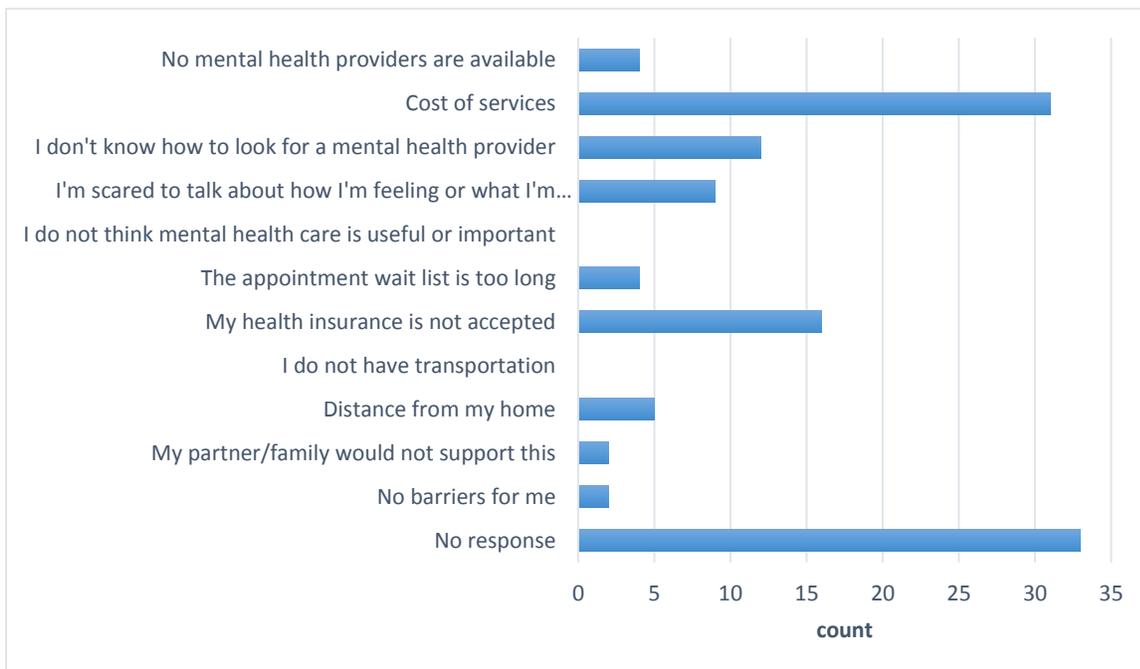
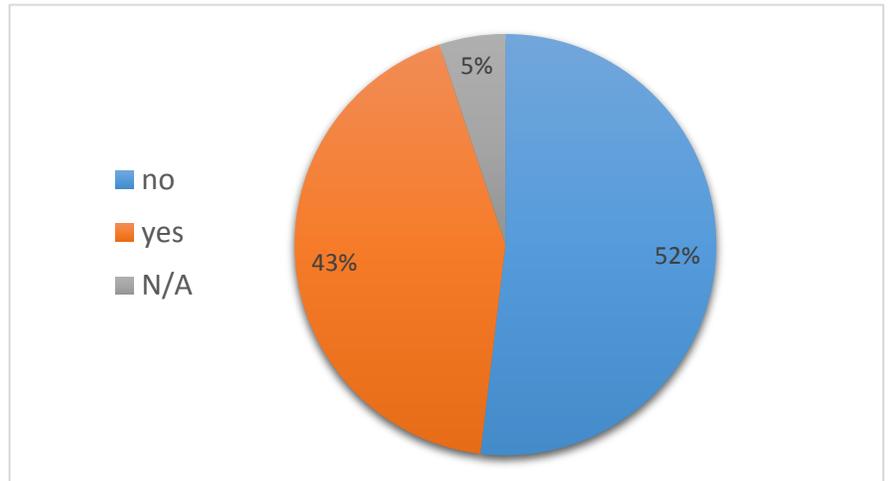


Figure 27. Are any of the following a barrier for you to get emotional/mental health care for fertility, loss, pregnancy or postpartum?

Two factors that have a demonstrated association with MMH problems are domestic violence and traumatic birth. Of the respondents to this survey, 3.8% responded positively to the question, “Did you experience intimate partner violence during pregnancy or within the first year after giving birth?” A much larger proportion (43.0%) indicated that they had experienced something traumatic during the birth experience (Figure 24).

Figure 28.

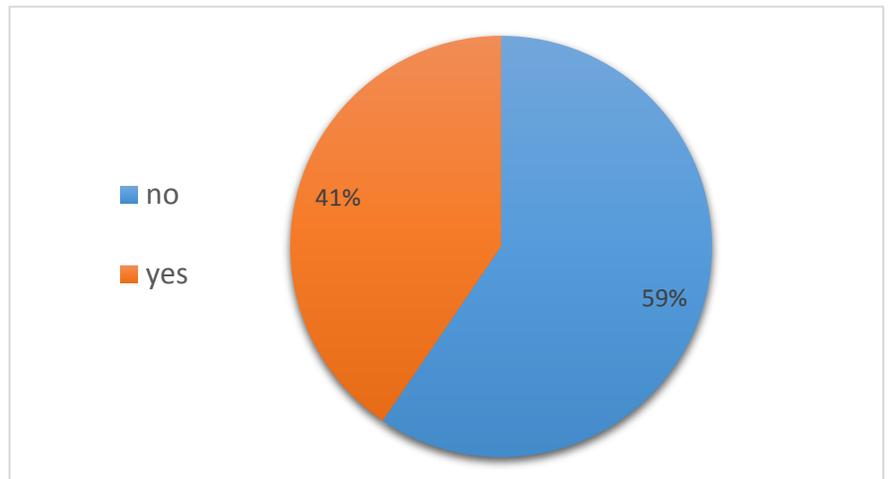
Was anything about your labor/birth experience that you describe as traumatic?



Changes in relationships with significant others have also been shown to have some association with MMH problems. Overall, 40.5% of respondents indicated that pregnancy or parenting have had a negative effect on a primary relationship (Figure 25).

Figure 29.

Has pregnancy or parenting had a negative effect on your relationship with a spouse/partner?



A final area of interest covered in the *Consumer Survey* was related to employer leave policies. The questions for this topic were as follows: “If you were employed when you gave birth, did

your employer provide time off/leave following delivery?” and “Was your time off paid by your employer?” Some respondents left one or the other of these questions blank but not in a fully consistent pattern (e.g., indicated that time off was not paid but left question for whether or not employer allowed for time off blank). Figures 26 and 27 summarize the responses to these questions.

Figure 30.

If you were employed when you gave birth, did your employer provide time off/leave following delivery?

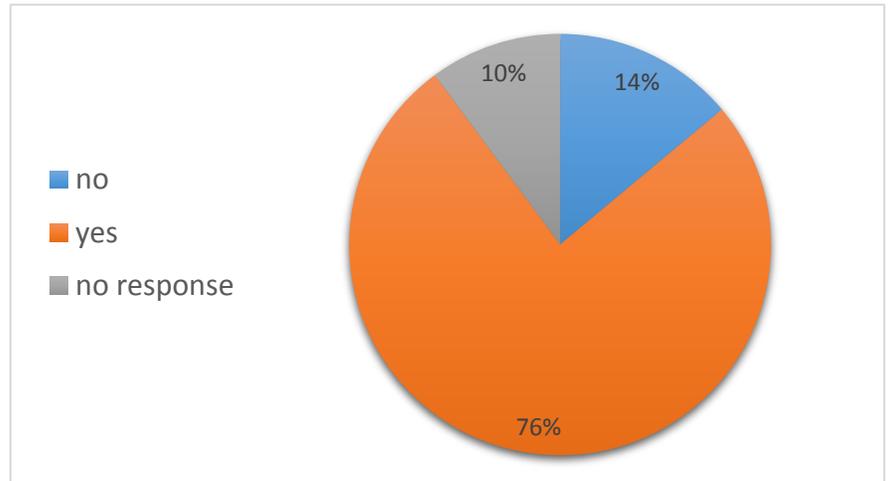
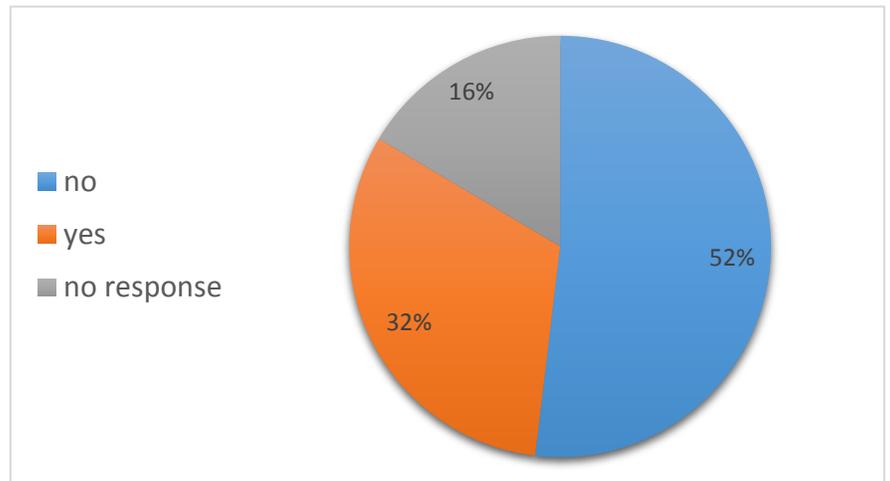


Figure 31.

Was your time off paid by your employer?



In addition, respondents were asked, “If yes and you took time off, how long was your leave?” Although this was a free-response question, the majority of responses were in the form of a number of weeks or number of months and could easily be coded into a numerical variable. Of the 54 specific responses to this question, the length of leave ranged from 1 to 36 weeks, with a mean of 10.4 ($SD = 6.0$) weeks. Five indicated that their leave was “indefinite” because they did not return to work.

MATERNAL MENTAL HEALTH CARE PROVIDER SEARCH

During the Kickoff Meeting with community stakeholders to identify areas of MMH concern, a common theme in many of the comments was lack of knowledge of available MMH care in our community. This theme contributed to three of the primary suggested goals: developing processes for referral for appropriate MMH care, reducing barriers to accessing appropriate care, and addressing fragmentation among service and care providers. We decided to address the theme of limited knowledge of MMH services by seeking information about potential MMH care providers as a consumer or medical practitioner might: by conducting an online search. We then contacted each mental health care provider identified in the search to ask several brief questions (described below). We identified this survey the *Mental Health Practitioner Survey*.

Our MPH intern—who has limited familiarity with the mental health provider community in our county—was the primary person collecting this data. She was instructed to approach this task as if she were a consumer or health care provider in a field other than mental health seeking a mental health care provider with a specialization in MMH. She used several online search strategies to identify any mental health care provider who has advertised as someone who provides MMH services. The search strategies included online searches through Google and provider lists provided through Psychology Today, through local health insurance providers, and through local hospitals. Although the search for specialized practitioners was systematic, we are certain that not all local providers of MMH care were identified through the online search, including at least two of the members of the ACPMHC (these practitioners do not advertise as specialists in MMH, so they were not missed through the online search). The goal of this search, though, was to find practitioner information that is readily available to those who are seeking MMH care, including both consumers and other health care providers.

The search for mental health practitioners advertised as specifically providing MMH care yielded a total of 15 practitioners. An attempt was made to contact each of these practitioners, but only 11 responded, for a response rate of 73.3%. Of the 11 respondents, 9 stated that they do offer specialized care for MMH; only 4 of these reported that they received formal training in MMH issues (Figure 28). Of the 4 reporting formal training, only two were able to be verified as recognized sources of training for perinatal mood disorders.

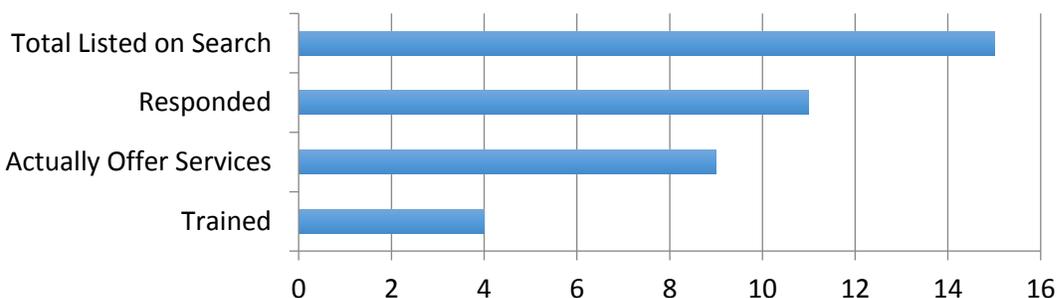


Figure 32. Maternal mental health care provider search: number of providers identified

PRIMARY DATA SUMMARY

As described above, we planned our “local listening” campaign on the basis of community-wide goals identified during our workgroup Kickoff Meeting. These goals included learning more about the following: local efforts to promote awareness and reduce MMH stigma, screening for MMH disorders, processes for referral for appropriate MMH care, barriers to accessing appropriate care, and fragmentation among service and care providers. We conducted our community assessment by surveying hospitals (via 2020 Mom’s *Whole Mom Hospital Survey*), social service agencies and medical practices (via the *Practice Survey*), individual medical care providers (via the *Individual Provider Survey*), and consumers (via a small focus group and the *Consumer Survey*). We also conducted a search for local Maternal Mental Health care providers. The fact that we obtained data from each of these sources is the primary strength of our community needs assessment. However, there were also significant limitations to our data collection methods, as will be detailed below.

Overall, our pattern of results indicates that the two local hospitals that provide maternal care are meeting some of the goals set forth by 2020 Mom; in addition, both are working toward meeting additional standards. Unfortunately, neither hospital currently meets enough standards to be qualify for recognition as a “Whole Mom” hospital. Although using the standardized 2020 Mom data collection instrument is a strength of our data collection process, one of the hospital respondents omitted a number of responses and instead wrote in “unknown,” so the data set was incomplete. The survey is designed to assess multiple aspects of care in a hospital setting, and it would be best completed by more than one person or by one person who has consulted with the appropriate colleagues.

We used a template provided by 2020 Mom (i.e., the *Local MMH Services Assessment Template*) for our assessment of both social service agencies and medical practices; we relabeled this the *Practice Survey*. We reasoned that a survey used in a larger-scale but otherwise similar MMH needs assessment process would be a good choice because our results could potentially be compared to the original project for which the survey was designed. We were thorough in our efforts to identify organizations that would be appropriate to survey for this project, assigning workgroup members to contact and follow-up with each organization, and managing returned data. Our planned methods of data collection and data management were strong; however, there were two primary limitations for this part of the needs assessment.

First, our overall response rate was low. We had an excellent response rate from social service organizations (i.e., 87.5%) and a very low response rate from medical practices (i.e., 23.1%), for an overall response rate of 38.2%. One potential reason for the low response rate from medical practices is that some of the questions seemed more targeted toward social service agencies (e.g., questions about funding sources and about direct provision of mental health care) than toward medical care organizations. Although we had intentionally used a survey that had been used by another group previously, it might have been more appropriate to use separate—and

perhaps different—questions for different types of organizations. Had the questions all been germane to medical practices, it is possible we would have had a better response rate from the practices. We were pleased that we received at least one response from each of the medical practice types we surveyed: ob/gyn, midwifery, and pediatrics. However, the low response rate from medical practices precludes generalization to all practices in the county.

A second limitation of the *Practice Survey*—one that is more significant for this project—is that it was not developed to specifically target the areas of interest identified by our community stakeholders during our needs assessment Kickoff Meeting. On the other hand, the survey responses are relevant to the identified areas of concern in our community.

Overall, the response pattern to the *Practice Survey* indicates that the services respondents most often provide for both maternal health and maternal mental health are educational. For maternal mental health in particular, 85% of respondents indicated that they provide education and awareness. Another 70% provide referrals for MMH treatment, and over 40% reported providing screening for MMH problems and/or MMH treatment. Based on this sample, it appears as if education, screening, and referrals for care of MMH problems is available within the community. At the same time, 100% of the respondents indicated that access to MMH care is a problem in our community.

When asked to rate potential barriers to MMH care in our community, the highest average ratings were for items focused on deficits of income or insurance rather than items focused on availability of MMH screening or treatment. When asked more specifically to identify potential barriers to making referrals for MMH problems, 100% endorsed the item, “Low public awareness of maternal mental health needs and available services,” and over 50% identified low professional awareness of MMH services available and limited professional cross-collaboration as barriers. A free-response question concerning what might improve MMH care in the community included several answers suggesting a need for improved education for consumers as well as better coordination of services.

Our third source of data was from a brief *Individual Provider Survey*. This was designed as an addendum to the *Practice Survey* but it was to be completed by an individual medical provider to assess more specifically patterns of screening and referral for MMH problems. The addition of these questions was meant to supplement the *Practice Survey* to more specifically address the issues raised at our project’s Kickoff Meeting. This was not designed as a means of assessing the overall practice patterns of individual providers within the community. Given the low response rate of medical practices to the *Practice Survey*, the response rate for this supplement should also be considered very low and not representative of the provider community.

Among the respondents to the *Individual Provider Survey*, 100% indicated that they routinely screen for MMH problems, with 80% screening at more than one predetermined time and 13% only when there is an indication of a problem. Two-thirds of the respondents use a validated

MMH screening measure. When asked what they do to address MMH problems, more than three-quarters indicated that they refer for counseling, one-third prescribe psychotropic medication, and one-third refer for psychotropic medication management. Overall, this pattern suggests that providers are screening for and either treating or referring for treatment of MMH problems. Of course, this is a very limited sample of providers.

Our initial data collection plan included conducting focus groups with medical providers and community members. Direct recruitment was used, with flyers posted throughout the community. Unfortunately, there was a low response rate to the postings, so the focus groups were canceled. Incentives can be used to increase participation in activities such as focus groups. For example, the 2016 needs assessment by WellFlorida included a \$20 incentive offered to focus group participants for their time. For a community-based organization such as ACPMHC, monetary incentives were not an option. Other potential types of incentive include moral obligation or responsibility, gifts, or goods. Our recruitment relied on moral obligation and—to a lesser extent—goods, in that we offered to provide refreshments. Although we were able to collect other data from consumers, the lack of community focus group findings is a limitation of this needs assessment.

Although we were unable to obtain information from consumers through community-wide focus groups, we were able to conduct a small focus group with a convenience sample of participants in perinatal support group. Participants in this group described barriers to obtaining MMH care including low education about MMH issues and resources available, lack of screening for MMH problems or lack of follow-up to any screening that did occur, and a sense of isolation. The other theme emerging from the group was needs, with the specific needs associated with the barriers: more visible information and education about MMH issues as well as more screening for MMH disorders.

To supplement the limited focus group information, we developed an online *Consumer Survey* to obtain data from community members. Although we had 79 respondents, this was very much a self-selected convenience sample. The respondents were recruited primarily through the ACPMHC mailing list and several Facebook groups related to pregnancy and parenting, although any respondent could forward information about the survey to relevant consumers or groups. Overall, the sample of respondents was primarily White/Caucasian, married, and well-educated, so it is not fully reflective of the community as a whole. In addition, because the survey was open to any respondent, there was no consistency in respondents' perinatal experiences. For example, some had given birth within the past 3 months, some had given birth over 20 years ago, and some had never given birth. Accordingly, the survey cannot be seen as assessing current practices or experiences within our county. Nevertheless, the survey results do provide information on consumers' experiences and attitudes.

Most of the respondents (95%) indicated that they had received prenatal education, most commonly education about childbirth, caring for a baby, and nutrition/exercise. When asked more specifically about receiving education about emotional or mental health during or after

pregnancy, 66% recalled receiving such education. Common sources of both types of education were respondents' doctors or care providers and the internet. With regard to screening for MMH issues, 75% recalled being asked questions and 58% recalled being given a questionnaire. Among those who completed a questionnaire, just over half recalled discussing results with a provider and about a quarter indicated that "nothing" happened after the screening.

Close to two-thirds of the respondents indicated that they had experienced emotional effects related to infertility, perinatal loss, or pregnancy / birth. The most common source of support during this period was family/friends, followed by a physician or therapist. When asked to rate potential barriers to seeking MMH care, 44% of the respondents omitted a response, which may suggest a lack of perceived barriers. Of those who did respond, by far the most common response was "cost of services."

Our final source of primary data was an online search for mental health professionals providing MMH care services. This search was essentially an analogue of what a consumer or medical provider would do if seeking a MMH care provider. We think that this novel supplement to the data provided by other care providers and consumers is one of the strengths of the study. This systematic search identified 15 providers who had self-identified (through their own online advertisement or through specialties identified on provider lists) as providing MMH services. Of those, 11 responded to a two question survey; 2 of these indicated that they do not provide MMH care. Of the 9 who said they did, only 4 had received formal training in MMH issues. Of these 4, only two reported sources of training that were verifiable and recognized for training in this specific area. This result suggests that there are few trained MMH care providers in the community. We know, however, that there are other mental health care providers in the community who have been trained and provide MMH care, but they are not identified as such in advertisements or provider lists. The limited number of trained practitioners located through the search seems to offer support for a recommendation for improved training of mental health providers as well as coordination of care.

Overall, the primary data we collected during our "local listening" campaign provides an indication of current MMH needs, care practices, and resources within Alachua County; however, we recognize the limitations of our collected data. Ideally, a future needs assessment of MMH in this area would address some of these limitations. Specifically, we would recommend the following changes to data collection methods:

1. a more thorough introduction to the purpose of the hospital survey so as to ensure that all of the questions are answered. Given the scope of items on the survey, it is likely that any hospital representative would need to consult with colleagues to provide an accurate answer to each item.
2. a more tailored method of surveying social service agencies and medical practices. The survey we used was fairly extensive, and the items would not all apply to both medical practices and social service agencies. A higher response rate might

be obtained by using separate surveys with questions that all seem to apply to a given organization type. Furthermore, the questions on this survey did not all address issues that had been raised in our kickoff meeting about MMH in our community. Designing a survey specifically to address our local question could be a more efficient use of survey time.

3. a representative survey of medical providers. We did not aim for a representative sample of medical providers, but such a survey could provide valuable insights.
4. a more targeted means of assessing consumers. Although the convenience sample we surveyed provided useful information, we did not obtain a representative sample of our current population. In addition, this survey was not limited to current or very recent experiences of respondents, so it does not necessarily provide a current “snapshot.”
5. addition of focus groups and key informant interviews, both of which could provide rich, first-person accounts of relevant experiences.

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