

Systems Issues Impacting Adequate Services for Postpartum Depression in Louisville Metro

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EXECUTIVE SUMMARY:

This KPHLI Change Master Project focused on a systems-level analysis of issues limiting adequate care for Healthy Start program clients in Louisville Metro affected by postpartum depression.

The Healthy Start program is a federal initiative operated by the Louisville Metro Department of Public Health & Wellness (LMPHW). Healthy Start staff members have observed that mothers who screen positive for postpartum depression either do not accept a referral for further counseling or do not keep their appointment. This is supported by data obtained during a grant performance review when only 7.3% of the clients that screened positive kept their referrals in 2006.

To identify barriers to follow-up, the KPHLI team collected qualitative data from Healthy Start clients, their friends, partners and family members, Healthy Start staff members, and providers of services for postpartum depression in the community. We identified barriers to follow-up for postpartum depression care similar to those identified at the national level. These barriers will be addressed through collaborative efforts to involve Healthy Start clients, staff, and direct service providers. Ongoing work is needed to build collaboration with stakeholders at all levels to structure and improve services and increase completed referrals for women with postpartum depression.

BACKGROUND:

Louisville Metro Department of Public Health and Wellness (LMPHW) is the grantee of the **Healthy Start** grant. It is a federally funded initiative received from HRSA (Health Resources and Services Administration). Healthy Start's mandate is to reduce the rate of infant mortality and improve perinatal outcomes through services to project areas with high annual rates of infant mortality. The Healthy Start program focuses on the contributing factors which research shows influence perinatal trends in high-risk communities. The Health Department has received this grant since 1997 and the current grant is in the fourth cycle.

One of the core functions of this grant is to provide depression screenings and referrals to Healthy Start clients that screen positive for postpartum depression. Postpartum depression is not recognized as a separate disorder from depression, according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV); rather it is a depression that occurs after childbirth¹. The World Health Organization defines depression as “a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. These problems can become chronic or recurrent and lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities”.²

In spite of the lack of distinction of postpartum depression as separate from depression, Riecher-Rossler and Hofecker Fallahpour assert that the use of the term is relevant because, “depression in early motherhood confronts us with specific needs.” The authors continue:

*“...help-seeking is often delayed due to shame and stigma, and diagnosis is often missed due to misinterpretation of symptoms. Services often do not meet these women's needs adequately, as they do not take into account their specific situation, problems and fears. Untreated, postpartum depression can have especially severe long-term consequences, not only for the mother but also for the child and the whole family. Therefore, special attention and special treatment is necessary.”*³

MedEdPPD.org, a professional education, peer-reviewed website developed with National Institute of Mental Health (NIMH) support, states that “[T]he reduction of PPD is a US priority healthcare need and a major public health concern.” According to the website, symptoms of postpartum depression include feelings of sadness, guilt, hopelessness, loneliness, helplessness, worthlessness, low self-esteem, confusion, agitation, loss of confidence, doubts, and the inability to laugh. Additional symptoms are anxiety, poor self care, inability to make decisions, exhaustion, feeling overwhelmed, appetite changes and excessive crying. Among the more serious symptoms are strange visions, scary fantasies and thoughts of hurting self or baby.⁴

Research shows that nearly 25% of all new mothers suffer mild depression, 9.7% show moderate depression, and 6.5% show symptoms of severe depression. Postpartum depression is most common among non-Hispanic Black and American Indian/ Alaska Native women.⁵

The LMPHW Healthy Start Program has five core service interventions: a) direct outreach; b) case management; c) health education; d) interconceptional care; and e) screening for depression. The program uses a multi-level system of case management. The program nurse gathers information and determines the level of medical and psychosocial risk by conducting a Risk Assessment for women. The appropriate staff then completes a follow-up and provides care based on the risk level. The case manager follows the woman throughout her pregnancy and later follows the infant and mother for up to two years.

There are specific neighborhood place areas in the western part of Louisville that have very poor birth outcomes. The Healthy Start project serves three of these neighborhood places. These areas show a high prevalence of minority communities and there have been persisting disparities between the white and African American population in IMR, fetal deaths, deaths from SIDS, adequacy of prenatal care and low birth-weight births.

One of the core functions of Healthy Start is to provide depression screenings and referrals to clients that screen positive for postpartum depression. Hence, after the client delivers her infant the program nurse does a post partum assessment of the client and screens her for depression. If the client screens positives they are provided with referrals and follow up. But in a recent performance review conducted by HRSA it was observed

that in 2006, 41 participants screened positive for postpartum depression out of 347 women screened through Healthy Start program. Nine accepted the referrals and only three of those nine completed the referral.

The trend of completed referrals declined significantly from 2004 to 2005. In 2004, all women who screened positive for postpartum depression were offered and accepted referrals; however, in 2005 and 2006 the number of women who screened positive for depression increased while the number of women accepting the referrals decreased 21.9% in 2006.

All women are screened for depression both during pregnancy and after pregnancy using the Edinburgh Depression Scale. The nurses perform this screening during the postpartum risk assessment visit. If the client has a depression scale of more than or equal to 10 the nurse offers a referral for counseling services. Similarly, the case workers ask the women at each visit “How would you rank your mood today?” If the client says fair or worse, the next question is “Why are you not in an excellent mood today?” If the problem of depression is identified by either the nurse or the case worker they offer referral to the client. If the client accepts the referral they even help them get an appointment and later follow up with the client and the agency where they have referred the client to. But it is observed that majority of the times the client refuses a referral. So the problem is two-fold: clients either refuse referrals or do not keep their appointments if they accept the referral.

The Healthy Start Program Evaluator regularly performs a comprehensive evaluation of the program-process, impact and outcome evaluation. Hence, she has complete access to the Healthy Start database that captures all information about the clients. Being part of the program the evaluator also has easy access to the clients through the consumer consortia. She follows all protocol to maintain the privacy and confidentiality of the client’s PHI (Personal Health Information).

Since postpartum depression is such a serious medical condition warranting intervention for the health and well being of the woman, her newborn and her family, nationally, two United States Senators are leading the charge that “aims to eradicate the devastating effects of postpartum depression on families”.⁶ Senator Robert Menendez of New Jersey and Senator Richard Durbin of Illinois have taken lessons learned from their personal family experiences and are advocating on behalf of women in the United States.

Legislation was introduced in the Senate in 2006 called The MOTHERS Act which will provide for increased education and access to screenings for new mothers and will increase research into this illness. This Senate Bill incorporates the House legislation, the Melanie Stokes Postpartum Depression Research and Care Act, which would expand and intensify research at the National Institutes of Health with respect to PPD and psychosis, including increased discovery of treatments, diagnostic tools and education material for providers.⁷

Two states have enacted legislation providing for the screening of women during the prenatal and postpartum periods for postpartum depression. The legislation in New Jersey was the first of its kind to offer hope to women with postpartum depression, through policy, to “lower the likelihood that new mothers will continue to suffer from this illness in silence”⁸. New Jersey was followed by the state of Illinois on January 1, 2008.

The legislation in Illinois, known as Public Act 095-0469, SB 0015, makes clear that perinatal mental health disorders are real and diagnosis and treatment are necessary. The Illinois law outlines when women will be offered screening and by what health care providers. The providers included are all licensed health care professionals providing prenatal and postnatal care, hospitals that provide labor and delivery services and licensed health care professionals providing pediatric care to infants.⁹ Understanding the reality of postpartum depression and the devastating impact it can and does have on families, the Healthy Start Programs nationally are emphasizing the completion of perinatal screenings and referrals for clients.

Problem Statement:

Why do Healthy Start participants who screen positive for postpartum depression not follow through with their mental health evaluation?

Behavior Over Time Graph:

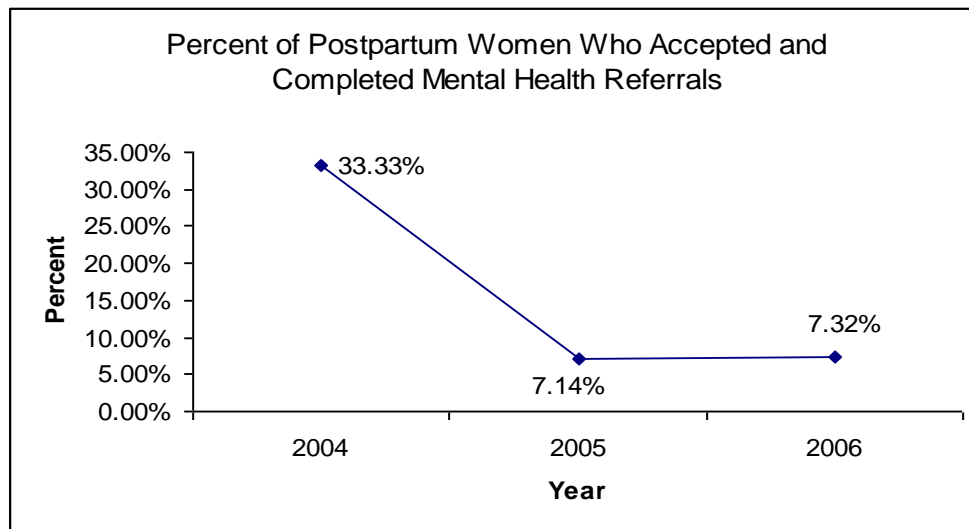


Table 1: Health Resources and Services Administration, Healthy Start

Causal Loop Diagram:

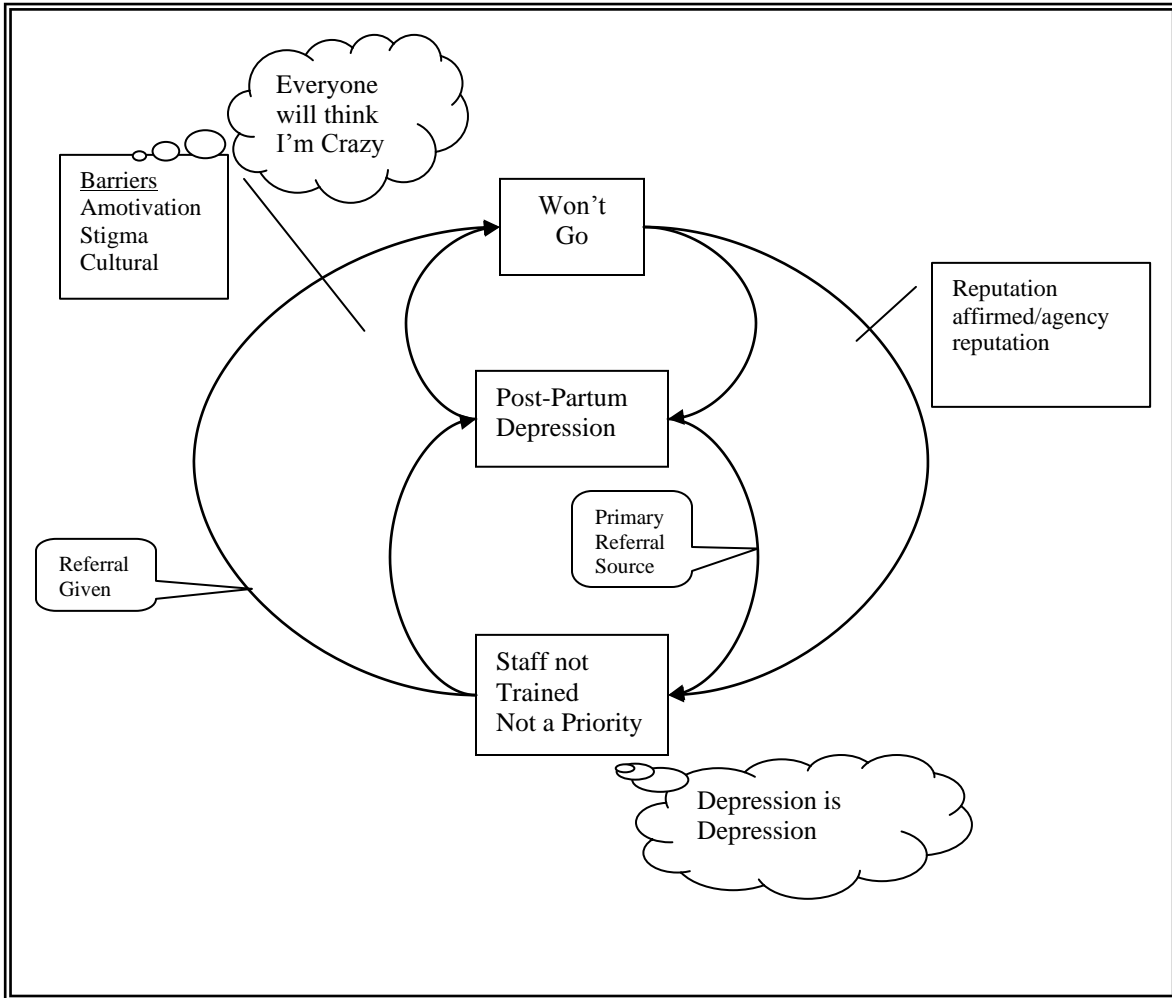


Figure 1: Causal Loop Diagram, Healthy Start Roadblocks

Essential Public Health Services and National Goals Supported:

Of the Ten Essential Public Health Services, and three Core Functions, our project supports those listed in the table below.

<i>Core Functions</i>	<i>Essential Public Health Services</i>
Assurance	Inform and Educate People re: Health Issues
	Ensure a skilled, competent public health workforce
	Evaluate effectiveness, accessibility, and quality of health services
Assessment	Monitor the health status of community
Policy Development	Inform, Educate, Empower
	Mobilize Community Partnerships
	Research and apply innovative solutions

Table 2: Adapted from the Core Functions of Public Health and the Ten Essential Public Health Services¹⁰

PROJECT OBJECTIVES:

1. Ascertain a comprehensive *list of barriers* to Healthy Start clients keeping referrals made for positive screens for postpartum depression; and
2. Identify *systems issues* impacting adequate services for postpartum depression in Louisville Metro.

PROJECT DESIGN:

1. **Study Design:** The one-shot case study design will be used. The clients have already been screened and offered referrals so this group of individuals will be surveyed to measure why they refused to follow up on the post-partum depression services. The current project aims to look into system issues impacting the services hence, emphasis will be made to survey/probe different systems; for example, clients are our major stakeholders but the staff that does the screening and provide referrals forms part of another system. The direct service providers are a major part of this system. Medicaid providers are the payee source and are part of this system that also affects services. The aim of the project is to connect these dots between the systems and look for gaps.
2. **Study Population:**
 - a) **Healthy Start Participants:** Female residents who give birth, live in the western Louisville neighborhood place areas and are Healthy Start clients. Age range varies

- between 18-45 years. 40-50 in number. Inclusion criteria- should be Healthy Start participants.
- b) **Healthy Start Non-Participants:** Family members (partners, mothers, grandmothers or aunts) and friends of the Healthy start clients. Age range >18years. Number 10-20
 - c) **Healthy Start staff** (nurses and case managers): Staff that conducts depression screenings and provides referrals. 18-20 in number.
 - d) **Direct Service Providers:** Local experts who provide services for postpartum depression to residents of Western Louisville metropolitan area.

METHODOLOGY:

Subject Recruitment Methods and Privacy:

1. Request Healthy Start case managers and nurses to inform potential clients about this project
2. Recruit the clients during Healthy Start Advocates meetings
3. Recruit clients during Healthy Start consumer sub-committee meetings
4. Request the program Administrator and Manager to allow the staff to provide input
5. Contact key informants in the community and identify members of agencies that provide postpartum depression services
6. The PI for this project is the Healthy Start program evaluator and has direct access to the Administrator and Manager of the program. This will help in recruiting the staff and clients for the focus groups. For the telephone survey, the PI will obtain information from the Healthy Start database about clients that screened positive for depression in CY 2006 and were provided referrals. The total number of such clients is 41.
7. The PI will request the case managers of these clients to inform them about this project. The PI will conduct the telephone survey herself.

(Please find attached the recruitment scripts for the different categories of respondents in Appendices)

Informed Consent Process:

The Healthy Start clients and their family members will be provided an explanation of the project during the recruitment process by staff members. Clients that agree to participate will be again provided information about the project and what it entails. The template consent form C will be used to obtain a written consent from the participating clients. The Healthy Start program does not have any clients that are Non-English speaking.

Research Procedures:

There are different systems that impact a woman's ability to get care for postpartum depression. But before we can look for system issues we plan to identify *potential barriers* at different points in the system of care for postpartum depression. To identify barriers there are three groups that need to be interviewed:

1. Healthy Start clients, their family and friends
2. Healthy Start staff, and
3. Providers of care.

Qualitative Methods using focus group interviews, telephone interviews, and key informant interviews will be used as research methods for data collection. The project will include assessments of:

1. Knowledge about postpartum(PP) depression;
 2. Barriers to getting care for PP depression; and
 3. Ways to enable completion of referrals for PP depression among each of these three groups—Healthy Start Clients, Providers of PP Depression Services, and Healthy Start Case Workers.
- Two focus groups will be conducted 1) with Healthy Start staff and 2) group with Healthy Start clients, their friends and family members;
 - Telephone interviews will be conducted with Healthy Start participants that screened positive for depression
 - Key Informant interviews will be done with Direct Service Providers

Resources:

Resources will be provided by the Director of Louisville Metro Department of Public Health and Wellness. The focus groups with the Healthy Start staff will be conducted at one of the neighborhood place locations that houses the staff. The focus group with the clients will be conducted at the same location (Ujima Neighborhood Place) where the monthly Healthy Start consumer group meetings are held and the person who coordinates those meeting will facilitate this focus group. If a client requests psychological support or counseling an onsite counselor from seven counties is available at Ujima.

RESULTS:

Key Informants about Postpartum Depression Services in Louisville

Sheila Ward

Before our team started interviewing any direct provider for postpartum depression in Louisville, we approached Sheila Ward for her input about the status of these services in our community. Our rationale for doing this was twofold, the Healthy Start clients keep their appointments if referred to Sheila Ward and two, and she is responsible for spearheading a task force to develop a directory of services for postpartum depression in Louisville.

Sheila is a OB/Gyn Nurse Practitioner in the University of Louisville who also specializes in Psychiatry nursing. She specialized in Psychiatry to show University residents a model for integrating mental health in women's health. CME Medical Grand Rounds are being developed for physicians' throughout the State. She trains residents, nurses at the state level. According to her as a systems issue, physician behavior is insurance driven. She explained that,

“....the Obstetrics/Gynecology physicians do not know how to treat postpartum depression and the mental health providers do not want the liability of treating a pregnant or postpartum woman since a child is involved. They are afraid to get into the litigation about medication for pregnant or nursing women. So the poor patients are stranded between two worlds.”

We asked her about the postpartum depression services available to our community and she stated,

“Seven Counties does little or nothing about PPD. Seven Counties’ mission is to take care of severe and persistent mental illness. PPD is temporary. People don’t qualify for disability. Seven Counties is not equipped to deal with PPD. Do not see people without a pay source. PPD clients do not have a reliable payment source so they do not want to see PPD clients.”

“Time of administration of the Edinburgh scale is very important but in University the screening is done at the first OB visit. There are several co-morbidities – substance abuse, paternity issues, 27% have a positive screen, but only about ½ are truly depressed. Other is adjustment disorder. Must ascertain/sort out what’s really going on. Ideally, 20-24 weeks postpartum to hook up with something already being done, routine such as a WIC visit.”

As listed above, insurance seems to be one of the barriers that affect treatment of PPD by the major Mental Health center in the community. Other barriers stated by her were,
“Legal issue of losing child custody to CPS, automatic default, boyfriend gets custody if mom is declared mental. What are the reassurance? ... can anybody in the legal system be educated that PPD is a condition? How to bridge this with the legal community?... That getting help for PPD is good thing, it means that you are a good mother ...can we package it?”

What should we do? Sheila had some very constructive suggestions about improving access to PPD services to women

- *Place a MH person in the neighborhood place*
- *Buy services of a mental health person trained in PPD for 1day a week*
- *Provide PPD in physical centers/community health centers since clients do not want to go to a mental health institution*
- *Educate the case managers and train them to al level where they can help-recommend good nutrition, adequate hydration, and sleep to moms*
- *each hospital offer a PPD support group*
- *Churches have a matriarchal hierarchy and excellent for penetrating the idea in the community*
- *Screen women enrolled in programs such as WIC, HANDS, Healthy Start*

Dr Cynthia Logsdon

Our team also requested Dr Cynthia Logsdon to be a key informant because of her vast experience in postpartum depression research. Dr Cynthia Logsdon is a nursing professor at the University of Louisville. Her research examines the effects of postpartum depression on mothers, children and families. She has also studied how the condition affects teen mothers and the long-term development of their children. She provided us with very useful information and resources about barriers clients face.

The main barriers that Dr. Logsdon has seen:

- *Stigma regarding mental health treatment; there is stigma going with Seven Counties, or the mental health provider of last resort*

- Wait time is a barrier
- Insurances can be a barrier—this is true across ethnicities—and there is a lack of equity in physical health care and mental health care
- For adolescents, they cannot receive mental health without parental permission. Adolescents are not emancipated for mental health

She stated,

“The federal government paid \$1 million to discover what you are trying to find. You should watch the 9 Barriers to care for postpartum depression on MedEd website. Another Healthy Start program has hired their own mental health professional to see all of the women who screen positive for PPD. This provider is available at an acceptable place (they checked with clients to get input about where, when professional would be available).”

Direct Service Providers-Clinical Providers

Our key informant Sheila Ward had provided us with a postpartum resource directory that consists of a list of health care professionals who had agreed to receive referrals for women with perinatal mood disorders. We selected from this list some providers who could potentially serve Healthy start clients and interviewed them.

We interviewed a provider at the Portland Family Health Center since this clinic is within the Healthy Start area. The provider is an ARNP and she follows pre-natal patients throughout their pregnancy. She screens for signs of depression and follows up with the patients 2 weeks after delivery to identify problem of postpartum depression as early as possible. In case of very severe there is a Psychologist Nurse Practitioner at the center. FHC Portland also has a Behavior Health Department where there are licensed Social Service Workers. If further treatment is needed the clients are then referred to Seven Counties. At the Center, they provide primarily individual counseling. The primary barrier that the provider mentioned was childcare, unwillingness to talk about their problem and language barriers with Hispanic clients.

Our team interviewed a clinical provider based in a hospital that serves women primarily in the eastern part of Louisville. The person was a licensed Clinical Social worker and provided services to at least seven postpartum women per week. She was knowledgeable about the different levels of postpartum depression and explained it very clearly in her answers, *“Mild Symptoms are recognized in individuals that sought treatment early on. They can go on into severity such as lack of sleep, difficulties making decisions, bi-polar depression. There can also be suicidal thoughts, struggles with scary thoughts (visions of wanting to harm their baby, but not carrying them out) they do not want to harm their baby but they continue to have the obsessive thoughts. They have feelings that their baby will be better off without them.”*

She has not encountered psychosis yet because that generally begins early after the delivery. If a case of psychosis were encountered then the client would be hospitalized first and then sent to the Social Worker. It was very evident from this interview that the provider was comfortable in providing counseling to women with postpartum depression, something that was not observed in any of the staff members of Seven Counties. But, for the purpose of Healthy Start referrals this person was not suitable because of the location of the hospital

since it is located far from our target area. The women residing in this area fall under a higher income group.

We talked to Dr Joyce Spurgeon, MD, who is the Director of Women's mental health in the University of Louisville. She manages patients who are depressed, throughout their pregnancies and thereafter. Her main interest is developing or setting up a support system for women. According to her,

"3-5 out of every 50,000 women are psychotic and can kill their infants if not treated. These symptoms can be seen within 3-14 days after delivery. Psychosis is predictable if risk factors are evaluated critically....10-20% women are depressed during pregnancy and physicians refuse to treat them because of the baby.really it is a woman's choice to take or not to take the medication during pregnancy. You should discuss the risk-benefit to her and prescribe a lowest safest dose.....a woman knows when she needs her medication...."

University of Louisville is in the process of opening a new Depression Center that will house psychiatrists, psychologists, residents and social workers. She hopes that the Center being a new facility with a cleaner environment will help them to attract clients in seeking treatment, but as she says,

"....you cannot completely remove the stigma of being labeled mentally ill since you believe that you are different than the person sitting next to you in the waiting room. I tell my clients that if you do not have attachment with the baby you may want to see someone....it is the approach."

She stated stigma of mental illness, parity loss, problems with payments from insurance and lack of education of the normal postpartum periods as some of the barriers that prevent clients to seek care for postpartum depression.

Another direct service provider listed in the Postpartum Resource Directory. That provider told us that counseling was not offered as a service at that office. Chiropractic care was the service offered for spinal and pelvic health after childbirth in conjunction with already established counseling services.

A support group was listed in the directory and we tried to schedule an interview with that agency but found that the group does not exist any longer.

It was also found that there is no focus on postpartum depression in hospitals prenatally.

Direct Service Providers-Mental Health System

Our team interviewed several personnel from Seven Counties since it is the major provider of mental health services in this area. For Medicaid patients this organization is the automatic referral source. It is also a major referral source for Healthy Start clients and for HANDS clients. The staff that were interviewed were from different levels of hierarchy both in terms of service provision and decision making process. We interviewed an executive level person, manager level, and three therapists who are in direct contact with women on a regular basis. From all the interviews it was found that the organization does not differentiate between Depression and Postpartum Depression which translates in their provision of services. The organization is very competent in providing services to the severely depressed clients but

does not have staff that is adequately trained in providing just postpartum depression counseling. Quoting the person,

“I am PhD in Clinical psychology and Child adolescent Specialist.

I do not have experience in providing services to many women here in 7C. I do not know what the percentage of women with PPD here would be, but it would be small, mainly treat clients with major depressive disorder.

We do not have adequate training specifically for treating PPD.

This was expressed in a comment made by the managerial level staff and it aligns perfectly with comments heard from the Healthy Start clients and our major key informant.

The State HANDS program has contracted with seven counties to provide postpartum depression counseling to their clients. Our team interviewed the therapist whose main focus is family and child therapy and works with mothers who have lost custody of their children, deal with parenting issues. When asked about services on postpartum depression she said, *“In terms of specialized programs (referring to PPD) I work with mothers to discuss parenting, PPD can impact parenting. I provide services to near psychotic to very minor transient cases, all situational bound, the mothers are so overwhelmed that they cannot handle being a parent; I see women showing signs of depression.”*

When we asked her, “How many staff members provide postpartum depression counseling? Are they housed in one or at different locations?” We were told,

“I have been identified as the point person in this program for HANDS. It is a specially created position, behavioral approach. I had thought that I would be overwhelmed with referrals from Jefferson County for PPD but I receive more from Shelby than from Jefferson county.”

There are two therapists that are co-located with Healthy Start in the two neighborhood places Bridges of Hope and Ujima. We asked them to summarize their experiences with providing services for postpartum depression and their responses were,

“The majority that I work with is teenagers not wanting the pregnancy, relationship break ups, pre-existing mental disorders, and types of abuse, (rape, over powerment, sex only).”

“Detox before seeing the client. Psychiatrist see patient once they are assessed by JADAAC as inpatient or outpatient. Within 48 hours the patient gets an appointment with the psychartitist.”

Barriers to getting care for postpartum depression

We asked Seven Counties staff about barriers that they have observed in providing services to clients with depression. One response from staff was *“To be clear on what our role is I put myself in the clients’ perspective, if you are struggling with basic needs how do you take care of MH issues....”*

These were some of the barriers listed:

Transportation-----

“Transportation---that is why we have no shows so we started a pilot to provide transportation...”

Language-----

“...Spanish-speaking clients from Shelby County and Somalians from Jefferson County.”

Insurance

“Clients ability to pay if not on Passport, one of my clients could not even pay \$5 for the session, she had no bus fare if she paid me.”

Cultural Barriers

“Screening Evaluations, which implies assumption that single Black Females are sexually promiscuous.”

“Fear of being labeled”

Trust

“...suspicion of DCBS taking your kids away”

Stigma

“I do not want to go to THAT place, that place is for crazy people.”

Fear of Medications

“Women don’t want to be on medication – fear by taking medicine it would put them back on the street.”

“Pill pushing - patients don’t want pills, especially when they have drug problem or pills represent insanity.”

Insurance System- Passport Health Plan

We interviewed staff from the Passport Health Plan (PHP) to see if their organization provided services for postpartum depression. We were told that they do not provide direct counseling services but provide referrals to their clients. PHP has a Mommy and Me program. This program receives referrals from providers throughout the community for pregnant women who have Medicaid or who are applying for Medicaid. Outreach representatives in the program call the women during their pregnancy to be sure appointments are being kept, provide referrals to services, referrals to HANDS and Healthy Start if appropriate. PPD screening is done by phone at 2 weeks and 4 weeks postpartum.

“PHP does not have a formal screening tool – ask how are you feeling? What is your mood? Are you having any sadness or depression? If yes, refer to nurse and the nurse calls for a more in depth interview. Nurse asks about any medications or if the client is planning to harm herself.”

“The clients are referred to 7 counties and to their OB if the client states that there is a problem. They are provided with crisis phone numbers. Educational materials are in the Mommy and Me handbook that all participants receive. Home visits are not made since there are too many members.”

Outreach representatives are visiting in the hospitals following delivery to remind them of their benefits and provide phone numbers.

According to the interview it seems that PHP does not have any formal set up either to access PPD services or provide referral. The clients are automatically being referred to Seven Counties since it is the major provider for depression in the area. There is no standard process for follow up of the clients that have been referred to seven counties. It would be safe to conclude that there is a major gap in the provision of PPD services to Mommy and Me clients.

Focus Group with Healthy Start Staff

The first interviews we conducted were with Healthy Start Program staff, including 3 nurses and 9 case managers, who conduct home visits with clients. The nurses have primary responsibility for conducting the Edinburgh Postnatal Depression Scale with their clients, but the case managers are in the home more often (1x/week) and can follow up with women as needed. Case workers ask the women at each visit “How would you rank your mood today?” If the client says fair or worse, the next question is “Why are you not in an excellent mood today?” The findings are discussed with the nurses during triage weekly. The teamwork between nurses and case managers helps ensure that changes in mood and other indicators of possible postpartum depression are identified and supported.

Staff members followed the Healthy Start protocol for an Edinburgh Postnatal Depression Scale score considered elevated. They indicated that they understood the need to be mindful of sharing information about postpartum depression in ways that would help affected women understand that the condition was not their fault.

“[I] discuss with the client possible reasons for postpartum depression: hormonal changes, because pregnancy has you off balance, body changes, physical and mental reasons. I choose descriptive words carefully and explain that there is nothing to be ashamed of.”

Staff members also mentioned the importance of emphasizing their desire to help the client to “be a good mom” by identifying and recognizing signs of postpartum depression and getting help. Written information is provided in a Healthy Start postpartum packet for all mothers.

Barriers to seeking follow-up care for postpartum depression included lack of transportation, child care, available time to schedule appointments, as well as cognitive barrier identified as a “lack of understanding that their symptoms will worsen over time.” Systemic barriers they identified were focused largely on the local mental health system specifically and a stigma about mental health in general.

“For 9 out of 10 clients a referral means like going to the Principal’s office if the client has never been exposed to MH issues. A stigma follows the referral.”

One staff member said that clients will feel like they are “crazy” if they have to go to Seven Counties, the local provider of community mental health services. There are few options for

postpartum depression care for women who receive Passport (the local Medicaid managed care program), and they don't have enough information about how much they would need to pay if they sought care from a provider who accepted a sliding fee scale.

My client tells me, *"I am going to be identified with that [mental health service provider]. . . even the look is depressing, people are smoking. . . . I do not even trust them. . . . [I] know what picture comes to my mind: a person who says the only thing I care about you is the Medicaid."*

". . . If I do not perceive that you really care about me do you think I will go? I feel that the clients should be given a choice."

In general there is a strong negative stigma associated with mental health issues and a mistrust of the mental health "system". Staff reported that their clients see the local mental health services as racist, broken, depressing, inadequate, and uncaring, a "welfare system" and a "lesser service". The magnitude of their mistrust of mental health services was expressed in concerns about having their children removed from the home if they are depressed, and the comment, "What do I have left if my mind is broken?"

Finally, culture provides barriers to seeking help for postpartum depression. Family and friends say: "We can handle our own problems; we don't need outside help. My mother and grandmother didn't seek help." Staff members have concerns about sending clients to the local mental health provider because of cultural concerns: "Are we being culturally sensitive when we provide clients referrals to a place that is perceived to be hostile?"

Suggestions for reducing barriers to services and helping Healthy Start clients complete referrals focused on developing trust between clients and mental health providers, providing choices in mental health providers for PPD, and developing a plan to share the need for referral with the client and write the referral for services.

Healthy Start Consumers, Families and Friends

Our KPHLI team arranged with the Healthy Start consumer group facilitator to hold a focus group for the purpose of gaining insight into their knowledge of postpartum depression, any experiences with mental health providers and their suggestions in ways to overcome barriers to receiving needed mental health services. There were fifteen participants that included consumers, spouses, mothers and friends. The participants appeared to be comfortable with each other and offered honest and thoughtful responses.

When asked about their knowledge of postpartum depression (PPD), one participant was quoted,

"It's a sickness just like cancer and you have to go to the doctor for help. You have to let your doctor know how you are feeling. Your emotions are up and down and you feel isolated."

Another stated,

“Some people won’t go to a therapist because you really have to trust a therapist. You don’t want to be judged or have people think you’re crazy. You just have to trust in the Lord and pray.”

One of the Healthy Start client’s spouse said,

“I didn’t know what was going on. Nobody had ever told me that this could happen and I felt so helpless. Men are supposed to be able to fix things and I couldn’t fix this. I had to really step up to take care of the baby and everything. I was really afraid. Why don’t doctors tell you this can happen?”

Barriers to Getting Care

All participants were very vocal in describing the barriers they think influence a woman’s decision not to go for help when screened positive for postpartum depression. There was much discussion around the providers in the community where women are referred for care for PPD.

“Seven Counties is the last place someone should be referred to. They don’t have the right kind of professionals available for what women with postpartum depression need. They only have social workers because they cost less to employ. That doesn’t help someone who needs or may need medications. You need someone who is a qualified therapist or a psychiatrist. That isn’t their specialty.”

“.....I do not want to go THAT [Seven Counties] place since all they want to give you is medication. I do not need medication, I just need to talk to someone....”

The following are some of the barriers listed:

What others may think

‘People will think I am crazy. They will think I’m not a good Mom. If they think I’m crazy, they might take my baby.’

Cultural stigmas

“Don’t understand how things work in my culture. Can’t speak my language.”

Time Constraints

“ I’m a single Mom and I don’t have time to go to appointments. I don’t have enough time to take care of me because I have so much already.”

No support system

“I don’t have anyone who can help me with the kids. You can’t go to an appointment and take all your kids, can you?”

Transportation

“I don’t have a way to get there except on the bus.” It’s too hard to transfer a couple of times to make the visit.”

Overcoming Barriers so Referrals for care are kept

The final question for the focus group was their suggestions for overcoming the listed barriers so that women who need care can receive it. Once again, the facilitator had to actively quiet the group and require hands to be raised to share. Here is what they had to say: *“Remind each woman how important she is and how much you (the case manager or home visitor) know she cares about her baby and her family. She needs to feel she has a reason to help herself and her family.”*

Others stated,

“Provide a choice of where you can go for help. People don’t all want to go to the same place. We are all different.

“There are lots of people to talk to – the social worker, your Healthy Start person, WIC and others can be resources. Don’t keep it to yourself.”

“Support groups would be good. That way women who are having the same problems can help each other. People won’t feel so all alone. You know other people have this too and can talk about it. We can help each other.”

“Provide education for all prenatal patients and their families. If we know this can happen, it would make it easier to understand why we need to have help. If you don’t understand, how can you know what to do or why it’s important. You don’t know it’s serious if you don’t know what it is.”

“..... I have enjoyed parenting classes and wanted to find something like that for PPD. I do know that some counselors do phone sessions, maybe that can help....”

“You have to find people you can work with. My daughter was diagnosed with ADHD and the 7C psychiatrist worked with me for a year. She did not prescribe any medication. She said she needed to know the family. After a year she prescribed a medication. If someone could tell us the symptoms...If you can talk to someone who has been through it, you realize that you are not as bad as you thought. Making connections is very important-keeping an appt is an inconvenience, too overwhelming.....”.

Results of Telephone Survey

A telephone survey was conducted with Healthy Start participants who had screened positive for postpartum depression. Telephone numbers of 56 participants who had screened positive for postpartum depression in 2005 and 2006 were extracted from the Healthy Start database. Out of 56 participants, responses were obtained for only 14 participants, in large part because the phone numbers were no longer in service.

Results of the survey showed that 78.6% of the participants surveyed were current Healthy Start participants and 21.4% were Healthy Start participants when they gave birth to their infant. Nearly all (92.8%) of the participants said that a Healthy Start nurse or case manager visited them after their child was born. Participants were screened for postpartum depression either by a nurse (71.4%) or by a case manager (28.6%). All respondents indicated that the

person who screened them had explained postpartum depression to them. The participants were also provided assistance in completing the Edinburg tool if they were unable to read the questionnaire themselves (43%). Only one respondent did not agree to the results of the Edinburg screening tool; the rest of them (93%) agreed. A majority of these participants (64.3%) stated that they were offered a referral. These participants were referred to Seven Counties Services (66.7%) and University of Louisville (22.3%). One of the participant said that she was given the crisis hotline as a referral. Seven out of nine participants accepted the referral. The two who did not accept indicated the reasons for declining the referral as,

Participant 1 “.....*Thought I could deal with it myself.*” **ED score=24**

Participant 2 “*I went to my OB/GYN, and she prescribed medication.*” **ED score=16**

Participant 1, who declined a referral, had a very high depression score but was unwilling to accept a referral. Out of the seven who accepted a referral only four kept their appointment and three did not keep their appointment. The three women who did not keep their appointments had been referred to Seven Counties Services. These three women had Edinburg depression scores ranging from 18-20 and had been advised by the nurse and case manager to seek help. As cited by these clients in answer to “What did the screening administrator say about your results?”,

“.....*Told me to see family doctor*”

“.....*She said I should probably get help*”

In response to the question, “will you recommend that your friends to go to that agency for counseling?” the clients said,

Participant 3 “*It was OK, but really didn't agree with what she said, so I went to the Pregnancy Resource Center.*” **ED score 18**

Participant 4 “*It was all right, she told me everything I already knew. I have a five-year old and participated in the HANDS program.*” **ED Score=24**

Participant 5 “...*Very, very helpful.*” **ED score=17**

Participant 6 “*Only talked to her once about calling if I had a crisis, but I didn't need to call her.*”

CONCLUSIONS:

MedEdPPD.org identifies nine major “roadblocks to treatment” for women with postpartum depression. They include: denying that a problem exists; feeling guilty; breastfeeding/medication issues; lack of support (perceived or anticipated) from family/peers; Limited access to resources: childcare, transportation; lack of funds/uninsured or underinsured; negative prior experiences with mental health; conflicting responsibilities/no time; and cultural issues¹¹. Our research identified the same barriers among Healthy Start women following through with referrals for postpartum depression. We also identified specific systemic issues that acted as “roadblocks.” We learned that the system for providing postpartum depression services in Louisville Metro is fragmented. As ascertained from interviews with clients, staff, and key informants, the primary break in the system involves the primary referral source—the local community mental health center.

Administrators at this center expressed a willingness to work with LMPHW and Healthy Start to provide optimal care to women with postpartum depression. Issues identified as needing attention include staff training in perinatal and postpartum depression and working with Healthy Start clients to improve access to service, and identifying opportunities to build trust between mental health center staff and Healthy Start staff and clients. Involving clients in the structuring of mental health services to meet their needs will go a long way to enhancing their willingness to follow up with mental health referrals. Previous research has shown that women’s clinic patients identified specific barriers to using mental health services-- transportation, childcare, and financial difficulties—yet indicated their interest in receiving mental health support in the form of therapy and/or classes about stress and health¹². In our focus group with clients we also found that clients do want to seek mental health services in form of a support system or an ability to talk to someone about their condition but could not because of lack of childcare. Therefore, reducing these instrumental barriers using a mental health provider, Healthy Start client partnership will enhance both patient trust in the provider and a patient-responsive system to meet client needs.

Ongoing work is needed to build collaboration with stakeholders at all levels to structure and improve services and increase completed referrals for women with postpartum depression. Improving services may include arranging support groups and/or group therapy options for women with postpartum depression, since social support has been shown to be helpful in normalizing symptoms¹³.

The identification of additional resources for supporting systemic change was a result of the team’s research. Among the resources to be integrated into this process are Behavioral Medicine’s new Women’s Behavioral Health Program and Family Health Centers. The former will provide a linkage for reaching and educating OB/GYN and pediatrics residents and physicians via Grand Rounds about Healthy Start and postpartum depression. These opportunities for education and discussion will serve to empower providers to diagnose, treat and refer women for postpartum depression.

Connections with Family Health Centers, which provide medical care for many Healthy Start clients, will ensure the involvement of their ARNPs and physicians in strengthening the identification and treatment of postpartum depression among health care providers. Improving connections with primary care providers will be helpful in enhancing the system in ways that result in improved conditions for women who experience postpartum depression. This has been borne out in previous research designed to identify primary care attributes that encouraged low-income African American women to seek care for depression. Results indicated that the provision of comprehensive services at the facility and a relationship of “mutual respect” between patient and provider “were found to be associated with greater rates of physician inquiry about and treatment for depression among vulnerable women.”¹⁴

The local Postpartum Resource Directory will also be updated to add these new partners and remove programs and providers who no longer provide related services.

DELIVERABLES:

Having completed the qualitative analyses on the focus groups and interviews of Healthy Start clients, staff, and community direct service providers, our team has analyzed existing barriers and identified systems issues to be addressed and deliverables to move toward positive change.

Healthy Start Clients – Involve them in structuring the mental health referral/follow-up system to best meet their needs by hosting discussions with the following at Health Start Consumers Meeting: UL Women’s Behavioral Health Program and Seven Counties Services.

Healthy Start Staff – Host psychiatrists at UL’s Women’s Behavioral Health Program for training/open discussion about postpartum depression, resources, client needs.

Mental Health Providers – Work with local community mental health center to help discuss findings and help build a support group for mothers, implement home visits, discuss ways to best meet the needs of Healthy Start clients in need of mental health services.

Medical Care System – we now have key contacts where we know our clients could be seen immediately with high Edinburgh scores. Work with psychiatrist at UL Women’s Behavior Health Center to develop grand rounds presentation to be presented to OB/GYN and Pediatrics. Meet with OB/GYN providers at UL Primary Care and Family Health Centers (FQHC) to present information about Healthy Start program, clients, client needs including postpartum depression follow-up and care.

Insurers – Meet with Passport Health Plan (Medicaid managed care) to discuss findings and implications for their Mommy and Me program for pregnant members.

LEADERSHIP DEVELOPMENT OPPORTUNITIES:

Paul Freibert

Healthy Start opportunities and challenges are wide ranging and touch all aspects of Public Health. As a KPHLI Scholar the opportunity to research, analyze, and bring research conclusions to Healthy Start issues allowed for many opportunities. These included interviewing Healthy Start staff and participants, developing research methods, and gaining an understanding of the issues. Through participation in this process certain leadership qualities came into play; including: patience, communication skills, project management skills, and working within an organizational structure.

Leanne French

Work with my team on the Change Master Project was the perfect culmination of the year of growth and learning afforded me by participation in KPHLI. All of the book learning and presentations—whether about tipping points, leadership, self-awareness, or learning organizations, or ethics—found practical application in our development of the Project. Much of the applied learning took place in the context of my team, and I'm grateful for their willingness to challenge me to grow through the project experience. From them, I've received honest feedback to support my professional development as well as the challenge to become a better listener and more competent leader. In all, my KPHLI experience has reinforced the importance of knowing myself as I work with internal and community partners to address change in creative, sustainable ways. I am grateful to have had the experience and look forward to moving forward as a more consummate public health professional.

Kay Heady

Working with my KPHLI team offered many opportunities for leadership development. Team processes were critical to the success of the project. By working on my own abilities to increase listening skills and have appropriate and meaning conversations, helped me be a better team member. Relationship development and personality understand made this a rich process and created a vibrant and productive effort. Communication with each other and with all Healthy Start internal and external partners was the key to our success.

Sarojini Kanotra

Kentucky Public Health Leadership Institute has given me a clear insight into my leadership skills and enabled me to reflect upon my strengths and weaknesses as a leader. As a result of my participation in the KPHLI, I was provided a unique opportunity to network with public health professionals from around the state. It was good to be exposed to the broader issues facing public health. Perhaps the most valuable part of my KPHLI experience was the Change Master Project. The reason I say this is because our team had the privilege to apply the concept of systems thinking in a hands on process. I enjoyed every part of our change master project because it presented our team with challenges at every step and we could walk

through each step like a mystery unfolding in every page. KPHLI's change master project is a great team building process and I feel profoundly enriched by being part of an excellent team.

Deborah Snow

Healthy Start has been serving the Metro community since 1998. As one of the first coordinator's of the Healthy Start Program we were charged with reducing infant mortality. The Public Health challenge of yesterday is still the same as today. Every child has the right to have a Healthy Start. As a KPHLI scholar the opportunity to work with the Healthy Start community has been immeasurable. KPHLI has allowed the development of team concepts to implement successful group discussion formats, project research conclusions, and the development of organized system strategies to bring awareness of Post Partum Depression to the community. This has created an internal and external leadership empowerment which continues to strengthen the community.

REFERENCES

1. Epperson C P. Postpartum major depression: detection and treatment. *American Family Physician*. 1999; 59:2247-2258.
2. World Health Organization website. Available at <http://www.who.int/topics/depression/en/>. Accessed March 20, 2008.
3. Riecher-Rössler A and Hofecker Fallahpour M. Postpartum depression: do we still need this diagnostic term? *Acta Psychiatrica Scandinavica*. 2003;108:51–56. Available at doi:10.1034/j.1600-0447.108.s418.11.x, accessed March 3, 2008.
4. MedEd, PPD, Mothers & Others, MedEdPPD.org MediSpin, Inc. website. Available at <http://www.mededppd.org/mothers/reference.asp>. Accessed March 5, 2008.
5. Women’s Health USA, 2006, U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA) website. Available at http://www.mchb.hrsa.gov/whusa_06/pages/introduction.htm. Accessed March 30, 2008.
6. Menendez, Durbin Bill to Fight Ravages of Postpartum Depression: Legislation proposes education, research grants to increase awareness and treatment of PPD. Senator Robert Menendez, Press Release, June 16, 2006. Available at <http://menendez.senate.gov/newsroom/record.cfm?id=257314>. Accessed March 31, 2008.
7. The Library of Congress, Thomas Home website. H.R. 20, reintroduced to Congress January 4, 2007. Available at <http://thomas.loc.gov/cgi-bin/query/z?c110:H.R.20>: Accessed March 31, 2008.
8. New Jersey Law Requiring Screening for Postpartum Depression Screening Goes Into Effect. Medical News Today website. Available at <http://www.medicalnewstoday.com/articles/54096.php>. Accessed March 31, 2008.
9. Public Act 095-0469, Illinois General Assembly, SB 0015. Illinois General Assembly website. Available at <http://ilga.gov/legislation/publicacts/fulltext.asp?name=095-0469&GA=95&SessionId=51&DocTypeId=SB&DocNum=0015&GAID=9&Session=>. Accessed March 31, 2008.
10. Centers for Disease Control and Prevention: National Public Health Performance Standards Program, The Essential Public Health Services. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention website. Available at <http://www.cdc.gov/od/ocphp/nphpsp/EssentialPHServices.htm>. Accessed March 18, 2008.
11. MedEd, PPD, Mothers & Others. MedEdPPD.org MediSpin, Inc. website. Available at <http://www.mededppd.org/roadblocks.asp>, accessed March 30, 2008.
12. Alvidrez J and Azocar F. Distressed women’s clinic patients: Preferences for mental health treatments and perceived obstacles. *General Hospital Psychiatry*. 1999; 21:340-347.
13. Scrandis Debra A. Normalizing postpartum depressive symptoms with social support *Journal of the American Psychiatric Nurses Association*. 2005; 11: 223-230.
14. O’Malley, Ann S, Forrest, Christopher B and Miranda, Jeanne. Primary care attributes and dare for depression among low-income African American women. *American Journal of Public Health*. 2003; 93: 1328-1334.

APPENDIX A

Edinburgh Postnatal Depression Scale¹ (EPDS)

Name: _____ Address: _____

Your Date of Birth: _____

Baby's Date of Birth: _____ Phone: _____

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt **IN THE PAST 7 DAYS**, not just how you feel today.

Here is an example, already completed.

I have felt happy:

- Yes, all the time
- Yes, most of the time This would mean: "I have felt happy most of the time" during the past week.
- No, not very often Please complete the other questions in the same way.
- No, not at all

In the past 7 days:

- | | |
|---|---|
| 1. I have been able to laugh and see the funny side of things | *6. Things have been getting on top of me |
| <input type="checkbox"/> As much as I always could | <input type="checkbox"/> Yes, most of the time I haven't been able to cope at all |
| <input type="checkbox"/> Not quite so much now | <input type="checkbox"/> Yes, sometimes I haven't been coping as well as usual |
| <input type="checkbox"/> Definitely not so much now | <input type="checkbox"/> No, most of the time I have coped quite well |
| <input type="checkbox"/> Not at all | <input type="checkbox"/> No, I have been coping as well as ever |
| 2. I have looked forward with enjoyment to things | *7. I have been so unhappy that I have had difficulty sleeping |
| <input type="checkbox"/> As much as I ever did | <input type="checkbox"/> Yes, most of the time |
| <input type="checkbox"/> Rather less than I used to | <input type="checkbox"/> Yes, sometimes |
| <input type="checkbox"/> Definitely less than I used to | <input type="checkbox"/> Not very often |
| <input type="checkbox"/> Hardly at all | <input type="checkbox"/> No, not at all |
| *3. I have blamed myself unnecessarily when things went wrong | *8. I have felt sad or miserable |
| <input type="checkbox"/> Yes, most of the time | <input type="checkbox"/> Yes, most of the time |
| <input type="checkbox"/> Yes, some of the time | <input type="checkbox"/> Yes, quite often |
| <input type="checkbox"/> Not very often | <input type="checkbox"/> Not very often |
| <input type="checkbox"/> No, never | <input type="checkbox"/> No, not at all |
| 4. I have been anxious or worried for no good reason | *9. I have been so unhappy that I have been crying |
| <input type="checkbox"/> No, not at all | <input type="checkbox"/> Yes, most of the time |
| <input type="checkbox"/> Hardly ever | <input type="checkbox"/> Yes, quite often |
| <input type="checkbox"/> Yes, sometimes | <input type="checkbox"/> Only occasionally |
| <input type="checkbox"/> Yes, very often | <input type="checkbox"/> No, never |
| *5. I have felt scared or panicky for no very good reason | *10. The thought of harming myself has occurred to me |
| <input type="checkbox"/> Yes, quite a lot | <input type="checkbox"/> Yes, quite often |
| <input type="checkbox"/> Yes, sometimes | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> No, not much | <input type="checkbox"/> Hardly ever |
| <input type="checkbox"/> No, not at all | <input type="checkbox"/> Never |

Administered/Reviewed by _____ Date _____

¹Source: Cox, J.L., Holden, J.M., and Sagovsky, R. 1987. Detection of postnatal depression: Development of the 10-item Edinburgh Postnatal Depression Scale. *British Journal of Psychiatry* 150:782-786.

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APPENDIX B

Script for Interviewing Healthy Start Staff

KENTUCKY PUBLIC HEALTH LEADERSHIP INSTITUTE
System Issues Impacting Adequate Services for Postpartum Depression
Focus Group Guide for Healthy Start Staff
November 19, 2007

Hello everybody, my name is _____. I will be facilitating today's meeting. Thank you for agreeing to come to this meeting today. . Research shows that nearly one out of every four new mothers suffers mild depression, about one in ten have moderate depression, and approximately one in seventeen show symptoms of severe depression. In the Healthy Start program we have observed that although some mothers screen positively for postpartum depression they either do not accept a referral for further counseling or if they accept the referral they do not keep their appointments. We are interested in exploring the reasons for this trend. We would like to get your input and try to better understand the problem.

The focus group should take approximately one hour. Before we get started, I would like to remind you that this study involves research. Your participation is completely voluntary. If you feel uncomfortable answering any of the questions, we can skip that particular question. There are no foreseeable risks to you as a result of participating in this study. In addition, there are no direct benefits from participating in this study, although the findings will help improve the services provided for postpartum depression. You may stop participation at any time without consequences.

In order to report accurate information, I am going to use a tape recorder during this meeting. This will help me in note taking. After the data analysis, the tapes will be erased and destroyed. Do I have everyone's permission to record this session? I also wanted to take a moment to assure you that your responses to these questions will be held in the strictest confidentiality – no names will be identified in the final report.

Do you have any questions before we get started? Great....If you have questions about this study later on, please contact Cynthia Lamberth at (859)257-5678 x82063 If you have any question about your rights as a volunteer in this research contact the staff in the Office of Research Integrity at the University of Kentucky 859-257-9428 or toll free at 1-866-400-9428. Just as a reminder..... If you have any questions or concerns during the session, please feel free to interrupt....here we go!

Interview Guide for Focus Group of Healthy Start Staff

- 1) Once you have administered the Edinburgh Postnatal Depression Scale, please describe the steps you take for the following:
 - a. Negative screening results
 - b. Positive screening results
- 2) How do you explain postpartum depression to your clients?
- 3) Describe your level of comfort with sharing results of this screening with your clients.
- 4) What would increase your confidence in sharing the screening results?
- 5) How do you encourage clients with a positive screen to accept a referral to a mental health provider?
- 6) What barriers have you identified for Healthy Start clients with positive screens for postpartum depression accepting referrals and keeping appointments?

APPENDIX C

Script for Interviewing Healthy Start Participants, Friends and Family

KENTUCKY PUBLIC HEALTH LEADERSHIP INSTITUTE
System Issues Impacting Adequate Services for Postpartum Depression
Focus Group Guide for Non Participants
November 19, 2007

Hello everybody, my name is _____. I will be facilitating today's meeting. Thank you for agreeing to come to this meeting today. . Research shows that nearly one out of every four new mothers suffers mild depression, about one in ten have moderate depression, and approximately one in seventeen show symptoms of severe depression. In the Healthy Start program we have observed that although some mothers screen positively for postpartum depression they either do not accept a referral for further counseling or if they accept the referral they do not keep their appointments. We are interested in exploring the reasons for this trend. We would like to get your input and try to better understand the problem.

The focus group should take approximately one hour. Before we get started, I would like to remind you that this study involves research. Your participation is completely voluntary. If you feel uncomfortable answering any of the questions, we can skip that particular question. There are no foreseeable risks to you as a result of participating in this study. In addition, there are no direct benefits from participating in this study, although the findings will help improve the services provided for postpartum depression. You may stop participation at any time without consequences.

In order to report accurate information, I am going to use a tape recorder during this meeting. This will help me in note taking. After the data analysis, the tapes will be erased and destroyed. Do I have everyone's permission to record this session? I also wanted to take a moment to assure you that your responses to these questions will be held in the strictest confidentiality – no names will be identified in the final report.

Do you have any questions before we get started? Great....If you have questions about this study later on, please contact Cynthia Lamberth at (859)257-5678 x82063. If you have any question about your rights as a volunteer in this research contact the staff in the Office of Research Integrity at the University of Kentucky 859-257-9428 or toll free at 1-866-400-9428. Just as a reminder..... If you have any questions or concerns during the session, please feel free to interrupt....here we go!

¹Women's Health USA, 2006: http://www.mchb.hrsa.gov/whusa_06/pages/introduction.htm

Interview Guide for Focus Group of Healthy Start Participants, Friends and Family

- 1) Are you familiar with the term postpartum depression?
- 2) If so, how would you describe it?
- 3) Are you aware that depression is a medical condition and it should be treated in a similar manner?
- 4) Do you think that a mother should seek medical advice for depression?
 - a. If no, why not?
- 5) Are you aware that severe depression in a new mother can affect the development of the infant?
- 6) Do you know which agencies provide counseling for postpartum depression?
 - a. Can you name a few?
- 7) Would you feel comfortable sending someone for counseling services for postpartum depression with the agencies you mentioned?
 - a. If no, why not?
- 8) How do you believe we should address the problem of postpartum depression in this community?

APPENDIX D

Interview Guide for Direct Service Providers

KENTUCKY PUBLIC HEALTH LEADERSHIP INSTITUTE

System Issues Impacting Adequate Services for Postpartum Depression

Interview Guide for Direct Service Providers

January 29, 2008

Hello _____, my name is _____. We are conducting this interview as part of a research project being conducted by a team from the Kentucky Public Health Leadership Institute. Research shows that nearly 25% of new mothers suffer mild depression, 9.7% show moderate depression, and 6.5% show symptoms of severe depression. Postpartum depression is most common among non-Hispanic Black and American Indian/ Alaska Native women¹. The Louisville Metro Department of Public Health and Wellness provides case management services to mothers living in the western part of Louisville Metro through a federally funded grant called the Healthy Start. Depression screening and referrals are core services provided by this program. In the Healthy Start program we have observed that although some mothers screen positive for postpartum depression they either do not accept a referral for further counseling or if they accept they do not keep their appointment. We are interested in exploring the reason for this behavior. For this purpose we would like to get your input and try to understand the problem in a correct perspective.

The interview should take approximately one hour to complete. Before we get started, I would like to remind you that this study involves research. Your participation is completely voluntary. If you feel uncomfortable answering any of the questions, we can skip that particular question. There are no foreseeable risks to you as a result of participating in this study. In addition, there are no direct benefits from participating in this study, although the findings will help improve the services provided for postpartum depression. You may stop participation at any time without consequences.

In order to report accurate information, I am going to use a tape recorder during this interview. This will help me in note taking. After the data analysis, the tapes will be erased and destroyed. Do I have everyone's permission to record the interview? I also wanted to take a moment to assure you that your responses to these questions will be held in the strictest confidentiality – no names or organizations will be identified in the final report.

Do you have any questions before we get started? Great....If you have questions about this study later on, please contact Cynthia Lamberth at (859)257-5678 x82063 If you have any question about your rights as a volunteer in this research contact the staff in the Office of Research Integrity at the University of Kentucky 859-257-9428 or toll free at 1-866-400-9428. Just as a reminder..... If you have any questions or concerns during the interview, please feel free to interrupt....here we go!

Date _____ Time _____
Name of Organization _____

¹Women's Health USA, 2006: http://www.mchb.hrsa.gov/whusa_06/pages/introduction.htm

Interview Guide for Focus Group of Direct Service Providers

- 1) Please summarize your experience providing services to clients with postpartum depression.

- 2) Do you provide services to clients with different levels of postpartum depression? Can you describe those levels?

- 3) How many staff members provide postpartum depression counseling? Are they housed in one or at different locations?

- 4) Which of the following counseling methods are available at your agency for women with post partum depression?

- a. Individual counseling
- b. Group sessions
- c. Telephone
- d. Home visits
- e. Other

- 5) What are the days and hours of operation during which postpartum depression services can be provided?

- 6) Do you offer any evening or weekend appointments?

- a. Yes, evening
- b. Yes, weekend
- c. Yes, evening and weekend
- d. None

- 7) In your experience, what barriers have you identified among clients seeking care for postpartum depression?

- 8) In your organization, how do you integrate the issues of cultural differences into your counseling of women with postpartum depression?

APPENDIX E

Telephone Survey Of Healthy Start Participants Who Screened Positive For Postpartum Depression

DIAL Phone #.

Hello. My name is _____. I'm calling for the Louisville Metro Health and Wellness. May I speak with _____?

IF DIFFERENT PHONE NUMBER

What is the new number? _____

IF CALLBACK

When would it be best to call again? _____

Hello. (IF NECESSARY, Is this _____?)

My name is _____. I'm calling for the Louisville Metro Health and Wellness. We are conducting a phone survey as part of a research project being conducted by a team from the Kentucky Public Health Leadership Institute. You were selected for this survey because you are either a current or prior Healthy Start participant. This survey will take about ten to fifteen minutes of your time and your participation is strictly voluntary. If you decide not to participate, there is no penalty or loss of any benefits to you or your agency. You also have the right to stop participation at any time. We do not anticipate any risk or adverse impact to you or your agency. We also do not anticipate any benefit to you or your agency as a result of your participation, however you will be helping us to identify barriers that do not allow mothers to follow up on their postpartum depression counseling. We will not collect personal identification information and all information you provide will remain strictly confidential. We will group the responses of all surveys and destroy individual forms and no names, addresses, phone numbers or other personal identifiers will be used when we report the results. You have an option to skip or not answer questions. Do you wish to participate?

IF YES, CONTINUE WITH, Thank you for agreeing to participate. If you have any question about your rights as a volunteer in this research contact the staff in the Office of Research Integrity at the University of Kentucky 859-257-9428 or toll free at 1-866-400-9428.

Date	Time	Outcome
1		BUSY SIGNAL
2		NO ANSWER
3		ANSWERING MACHINE
4		NOT IN SERVICE
5		PARTIALLY COMPLETED
6		TERMINATION
7		HANGUP
8		CALLBACK
9		REFUSAL
10		LANGUAGE BARRIER

Telephone Survey Of Healthy Start Participants Who Screened Positive For Postpartum Depression

Q1) Are you a current Healthy Start participant?

- a. Yes b. No

Q2) IF NO, Were you a Healthy Start participant when you gave birth to your child?

- a. Yes b. No

INTERVIEWER INSTRUCTION: IF NO FOR BOTH 1 AND 2, TERMINATE

Q3) Did a Healthy Start nurse or case manager visit you after your child was born?

- a. Yes b. No

Q4) Who screened you for postpartum depression?

- a. Nurse b. Case Manager

Q5) Did the person who screened you explain to you about postpartum depression?

- a. Yes b. No

Q6) Did you complete the questionnaire yourself about depression or did the staff member read the questionnaire to you?

- a. Yourself b. Staff Member

Q7) What did the screening administrator say about your results?

Q8) Did you agree with the results?

- a. Yes (GO TO Q10) b. No

Q9) What was the reason that you did not agree?

Q10) d she offer you a referral?

- a. Yes b. No (COMPLETE)

Q11)To what provider or agency were you referred? (READ IF NECESSARY)

- a) Seven Counties
- b) University of Louisville
- c) Norton Hospital
- d) Dr Spurgeon
- e) Sheila Ward
- f) MH Services
- g) Crisis Hotline
- h) Other _____

Telephone Survey Of Healthy Start Participants Who Screened Positive For Postpartum Depression

Q12) Did you accept the referral?

a. Yes (GO TO Q14)

b. No (GO TO Q13)

Q13) Why did you decline?

INTERVIEWER INSTRUCTION: COMPLETE FOR THOSE WHO ANSWER Q13

Q14) If yes, did you keep the appointment?

a. Yes

b. No

INTERVIEWER INSTRUCTION: COMPLETE FOR THOSE WHO ANSWER NO

Q15) How would you describe your experience with the service provider?

Q16) Will you recommend that your friends to go to that agency for counseling?

a. Yes

b. No 502-290-1578502-290-1578(GO TO Q17)

INTERVIEWER INSTRUCTION: COMPLETE FOR THOSE WHO ANSWER YES

Q17) Can you give us your reasons?
