

## Appendix II: Summary of Survey and Focus Group Findings

“Health is not *just* the outcome of good medical care, but is the result of environmental, economic and behavioral choices, and how an individual prioritizes their own health or that of their child based upon the challenges and choices they make on a daily basis.”

### The Comprehensive Prenatal-Perinatal Services Networks 1987-2007 Report

As part of its tri-annual perinatal needs assessment, MVPN gathered information on barriers to health care and support services for women, children and families by means of a survey and focus group discussions. The survey drew information from twenty health care and human services agencies and organizations. The eight focus groups provided a venue for thirty-three pregnant women, new mothers, and partners/fathers to share their experiences with health and human services within our community.

The following summary combines these information sources. Overviews of surveyed agencies and the focus groups are followed by sections devoted to specific issues. These begin with information drawn from the surveys. ➤ Paragraphs marked with this stylized arrow convey information women shared either with the agencies or within the focus groups.

### **Overview of Surveyed Agencies**

The numbers of clients served by each of the twenty agencies surveyed ranged from well under 100 to over 10,000. The agencies/organizations offering services range from a single site organization that serves primarily local clients, to multiple site organizations that serve clients across the region or country. They include state, county, private, and church-based organizations and offer services ranging from education programs to surgical procedures to help in filling out forms. The health issues represented by these agencies also has a broad range, and includes pregnancy, birth control, nutrition, domestic violence, mental health, food insecurity, financial insecurity, drug abuse, developmental delays, and sexually transmitted disease.

The question of differences between un- or underinsured and insured patients regarding the scheduling, treatment, compliance, and financial activities generated the least number of answers from respondents: twelve of the respondents did not contribute answers. In part this lack of response could reflect a two-tiered system that limits perspective to the served group. Nine of the twelve stated that they serve a homogeneous group, either all insured clients or all or mostly uninsured/low income clients.

Among the agencies surveyed, ready knowledge of demographics concerning client pregnancy, parenting and identification of infants as clients is apparently low; opportunities for making referrals may be correspondingly low. For instance, nine of the twenty respondents did not have numbers to report on how many of their clients are pregnant or parenting an infant.

The issue of missed appointments is an important one. Agencies strive to maintain contact with their clients: seeing clients when the clients are able to come in, making an effort to teach clients to call ahead if they must miss an appointment, allowing clients to reopen their case at a later date, continuing to attempt contacts for several weeks or months, and using “the public health model of continually providing the information until the individual is ready to accept it.” The

importance of keeping appointments was stressed by one agency that noted that for their clients, a missed appointment with a provider means being discharged.

### **Overview of Focus Groups**

In the Spring of 2008, Mohawk Valley Perinatal Network collaborated with a team of students and faculty from Colgate University to conduct research into issues surrounding maternal and infant wellness in Mohawk Valley. The research focused specifically on issues of access to pre and postnatal health care in the region. As part of information gathering, eight focus groups were facilitated by students from Colgate University. Conversation was generated by a questionnaire provided by Mohawk Valley Perinatal Network. Colgate University's Institutional Review Board (IRB) reviewed and approved the research protocol.

Flyers at community locations and promotion by organizations that partner with MVPN attracted thirty-three attendees to the group. It should be noted that while men were included in the plans for the focus groups, there was little success in recruiting them to the sessions. Among the attendees, the Women, Infant and Child (WIC) Program was the most prevalent healthcare provider used. Almost all of the individuals had heard about the program before their pregnancy and determined it to be of assistance. In addition to WIC, many of the women used both Medicare and Medicaid. Those participants not qualifying for Medicare and Medicaid often utilized the Pregnancy Care Assistance Program (PCAP) as an alternative.

### **Concerns and Barriers to Service: General**

#### *Transportation*

Respondents considered problems with transportation as a cause of a significant gap in services to women and infants; it was the hindrance to care most often named by respondents. They considered it to have a role in incomplete referrals and in the difference between under and uninsured clients and those with insurance. It was also pointed out that access to quality food often depends on transportation.

While most providers indicated that their offices are in locations that have access to public transportation, few providers indicated that their services were used mostly on a local basis. Estimates of distance traveled ranged from within five miles to thirty miles or more. Additionally, agencies commented that some clients are reluctant to use public transportation.

➤ Women also reported to agencies that the cost and availability of transportation was a significant problem. In the focus groups, transportation issues were frequently raised, including the inconvenience of using buses to travel between agencies in the same day, and the problem of carrying supplies, such as cans of formula, that they received from agencies.

#### *Office Hours*

Inconvenient hours were mentioned as a reason for lack of client follow-through several times over the course of the interviews. The great majority of office hours take place Monday - Friday between the hours of 8:30 and 4:30 pm. Delivery of services is limited outside of these hours.

➤ Clients also noted that limited outreach office hours were a barrier to service. In particular the work-day hours of many agencies created problems for those who are marginally employed. Comments during focus groups pointed to the dilemma of those who have inflexible work hours, lose pay, or have their work hours cut back if they take time during the work day for appointments.

### *Range of Services*

Few of these providers screen clients and provide health education on the topics of safer-sex or nutrition and weight management. One of the agencies that offers safer-sex services reached capacity eighteen months ago. Another reported that its parenting programs are full.

➤ In keeping with this information, women reported that food programs and alternatives for family planning services were not readily available to them. Many women in the focus groups commented on nutritional information that was offered to them: much of it was in the form of written material and much of it focused on nutrition during pregnancy. Very little information was geared to nutrition for the baby. Several women in a focus group commented that they would be very happy to find a class that could teach them how to take care of their baby.

### *Client Follow-through*

Many respondents commented on lack of client follow-through. Several explanations for this were offered:

- Language and cultural barriers (including a different perception of time)
- Clients living in crisis (including mobility)
- Client discomfort with the referral (including a reluctance to have a home visit and lack of acceptance of the indicated next step)
- Financial constraints (lack of ability to pay and lack of providers that take Medicaid)
- Inaccessibility of services (inconvenient time and/or location, transportation, wait times for an appointment, and difficulty of paperwork).

➤ Clients themselves reported to agencies that it was difficult to reschedule missed mental health appointments.

### **Concerns in Delivery of Services**

Agency answers to the question of significant concerns in the delivery of services to pre- and post-natal clients were expressed in terms relative to: the role of the agency, problems systemic in the culture/society, and the lives or actions of their clients. Overall, the concerns expressed most often addressed retention and education.

#### *Role of the Agency:*

- Recruiting, enrollment and retention, for instance, getting people in early and convincing clients to come back for services after pregnancies
- Explaining about payment options
- Finding resources clients need

- Treating a client humanely, insuring a positive experience
- Managing pain

*Problems systemic in the culture/society:*

- Obesity rate
- Lack of education for young women on preventing pregnancy
- Cultural norms accepting of teen pregnancy, alcohol, and drugs
- Poverty
- Lack of parent education
- Homelessness

*Lives or actions of their clients:*

- Being distracted and busy with home/children; not feeling well/tired
- Completion of a program that involves multiple visits over several months
- Medical problems during pregnancy (e.g. diabetes)
- Fear that the system wants to catch them
- Lack of family support
- Availability of baby supplies

➤ The role of family was evident in the focus group discussions: many women reported that they relied on family for such things as health care advice and hand-me-down baby supplies. The other side of family influence was brought up by a focus group member who related her boyfriend's negative reactions to her changes in the household meals to include more variety and healthful ingredients.

➤ Humane treatment was brought up in a number of focus groups: participants commented on the perceived rudeness of social services staff and the impersonal treatment from some healthcare providers.

## **Barriers to Services**

The significant barriers identified by agencies:

- Financial barriers, including lack of funding for the agency and the cost to clients
- Language (One provider's client base brings over 40 languages)
- Inattention to culture-specific concerns, such as a need for interpreters
- The difficulty of understanding the different requirements of various programs
- Fear of the system and "getting bounced around"
- A lack of childcare
- A lack of targeted marketing efforts
- Cultural differences

Also, a need for education was mentioned as was early identification for pre-natal care and appreciation for the importance of pre-post natal care. While paperwork was not specifically mentioned in answer to this question, it was mentioned in answer to four other questions and may be a factor in services to this group. For instance, the difficulty of paperwork was cited as a common reason that referrals were not completed, and as a barrier to women applying for

Medicaid, SCHIP or other insurances. Making paperwork easier for those without insurance was recommended by an agency that noted the uninsured wouldn't come in for services.

- Women reported that waits in line for public assistance were a barrier to access, as did the participants in the focus groups. The cost and availability of childcare and baby supplies was also reported by women as a barrier. Inhibitive paperwork was discussed in focus groups; the difficulty of applying for food stamps prevented a focus group participant from pursuing that option.
- An aspect of language that was brought up by focus groups members was the use of medical jargon that they found difficult to understand. Also, much of the educational material offered to women is reading material, and therefore relies on a presumed level of reading proficiency. At least one focus group member reported that the reading level was too difficult for her.

## **Insurance Coverage**

### *Comparison of insured and uninsured experience*

As noted above, the ability of surveyed agencies to compare the experiences of insured and uninsured patients is limited. An agency that offers disaster services regardless of insurance coverage notes that people with insurance take less help, while another agency noted that those without insurance are hesitant to access services for themselves or their children. A third agency, which offers a sliding fee, commented that the uninsured won't come to their office for services. An agency that works with both populations commented that the insured clients tend to come to appointments, while the uninsured don't have transportation or can't wait for long appointments. They also commented that the uninsured sit in the waiting room longer.

- One of the women in the focus groups had experienced peri-natal health care first under private insurance and then as a patient who qualified for PCAP. She noted that she received more extensive care, with staff taking far more time with her and offering more educational services under PCAP. On the other hand, she also noted that at some agencies their approach was geared to the population they served and did not take into account differences among the clients.

### *Barriers to Application*

Several barriers that keep women from applying or qualifying for insurance were mentioned by respondents, with no one barrier emphasized:

- Unemployment and cost of insurance
- Lack of knowledge or education
- Language and culture
- Paperwork

The question of barriers that keep women from applying or qualifying for Medicaid or SCHIP brought out issues that pointed to the negative experience of applying for Social Services:

- The stigma of applying
- Not wanting or able to negotiate the system
- Difficult paperwork, and language barriers.

- New regulations that result in clients believing that they did not qualify
- The stipulation that women must take the child's father to court for child support

As well, making too much money to qualify for Medicaid but not enough to afford insurance was reported as a barrier, as were the conditions of developmental disability, mental illness, and being undocumented. One respondent believed that most women are just overwhelmed.

➤ Agencies did not indicate that women reported to them about difficulties with insurance. However, this was a frequent topic in the focus groups. The problem of making too much to qualify for various programs was commented on, as were difficulties in Medicaid recertification. Gains in income affected coverage, and women reported that they had to either fight the loss of their coverage, look for other programs to cover medical expenses, or absorb the increased costs.

➤ Social Services staff was reported in the focus groups to be often unfriendly and the paperwork very time consuming. Additionally, participants confirmed the agency statement that some women did not want to take the fathers of their children to court. The range of experiences of women in the focus groups indicated the complexity of this issue: one father was a fifteen-year old high school student, another a disgruntled ex-husband, and another was unknown to the mother.

### **Reported Gaps in Services**

One agency reported no real gaps in services to women and infants and attributed that to the good working relationships they had with other agencies. Other agencies pointed out the:

- Need for more communication between clinics
- Lack of providers, specifically that no hospital delivers babies in Herkimer County
- Need for a nonjudgmental environment, culturally appropriate services
- Gap in insurance coverage for those between college and their first job
- Lack of consistent parenting management over age 21
- Lack of affordable and conveniently located housing
- Lack of affordable infant care
- Problems with transportation
- Lack of choices
- Inadequate recognition of different cultures
- Need for adequate staffing

Beyond those services mentioned elsewhere, agencies reported that women have indicated that these services are not readily available to them:

- Services related to childcare: Even Start, WIC
- Services that address domestic violence
- Health care other than for pregnancy

Women also reported these barriers to service:

- Waits in line for public assistance
- Cost and availability of childcare and baby supplies
- Number of primary care providers not taking new patients

➤ During focus groups, women also indicated that they needed childcare during medical appointments. The number of interruptions to focus group conversation by babies and small children gives some indication of the experience of women who must bring their small children with them to medical appointments.

➤ Also during the focus groups, participants complained that they could not get whole or 2% milk through WIC, even for low weight babies. Another participant complained that she could get daycare for her work hours but not for the hours she attended college.

### **Current Efforts to Improve Services**

Reported efforts to reduce the perception by women that services are not readily available to them due to lack of insurance, being a minority, having a language barrier, being a single mom, or being a teen mom (self-stigmatization) took the form of:

- Targeted outreach/marketing
- Easily accessed locations such as schools and outside clinics
- Efforts to treat people well, for instance through individual attention and building relationships, treating everyone the same
- Providing an interpreter
- Employing an active social worker

One agency commented that targeted programming brings in women and that women have to be found, particularly those who are at work during program hours. Although hours of service are reported as a problem by agencies and their clients, only one agency mentioned extra hours as part of their effort.

### **Recommendations for Capacity Development**

Respondents had a variety of ideas about capacity development that would help them serve their clients more effectively:

- More money, more staff, better transportation
- Closer interactions between agencies
- A more centralized referral development and updating agency
- Better outreach/marketing and recruitment
- Retention efforts that address homelessness, mobility, and the number of students leaving school.
- Development of well services between pregnancies
- Affordable interpretive services
- Easier paperwork for those without insurance
- More space and staff to address outgrown facilities