Case Management: A Method of Addressing Subject Selection and Recruitment Issues

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INTRODUCTION

Enrolling pregnant substance-using women into chemical dependence treatment continues to present a major challenge for social services and health care professionals. Recruitment problems are exacerbated further when enrollment includes participation in a clinical trial. In 1989 Washington State embarked on a 6-year research and demonstration project funded through the National Institute on Drug Abuse (NIDA) to study optional treatment modalities and the recruitment of pregnant substance-using women. The project was implemented in Washington State as the King County Perinatal Treatment Project (MOM's Project). Project researchers hypothesized that pregnant substance-using women and their infants would have improved pregnancy and child development outcomes if mothers participated in chemical dependence treatment during pregnancy. Project eligibility criteria required women to be in their first or second trimester of pregnancy (prior to 28 weeks gestation), be older than age 16, and have a diagnosis of chemical dependence.

This chapter describes the difficulties and successful strategies associated with recruiting pregnant women into chemical dependence treatment under the auspices of a clinical trial. Some of the recruitment problems were associated with the refusal of the women to participate in a clinical trial. Other problems were related to the nature of the disease of chemical dependence. Still other problems stemmed from the reluctance of social services and health care providers (traditional gatekeepers) working with this population to refer clients for treatment. The success of the recruitment efforts resulted from use of community maternity case managers as primary recruitment agents. Recruitment strategies incorporated a project philosophy of patient recovery and used recruitment scripts that featured brief motivational interviewing techniques.

A major ameliorator of the negative consequences of alcohol and other drug use during pregnancy is participation in chemical dependence treatment. Preliminary findings of the MOM's Project suggest a positive

trend in pregnancy outcomes for women who remain in treatment 90 consecutive days or longer. For example, these women have demonstrated a reduced likelihood of delivering preterm babies (less than 37 weeks gestation), experiencing intrauterine demise or neonatal death, delivering babies who produce a positive toxicology screen, and delivering babies who require an extended hospital stay.

RECRUITMENT CHALLENGES

Recruitment can be considered a two-stage process: *finding* pregnant substance users and *engaging* the women into treatment. Agencies in contact with pregnant substance-using women may fail to make referrals for treatment, although a majority of these women eventually become known to community social services and health care professionals. These gatekeeper clinicians are often reluctant to confront women about their chemical use for fear the women will stop using prenatal and other services. Clinicians also may be unaware of the availability of chemical dependence treatment in their community, lack the skill to recognize addictive diseases, or have negative impressions of the efficacy of treatment.

There may be few referrals even when other chemical dependence treatment agencies are involved. The chemical dependence treatment providers outside the MOM's Project resented the use of non-chemical-dependence personnel as recruiters. They expressed concerns that project case managers "enabled" pregnant women by providing them an array of support services that reduced the consequences of drug-using behavior.

If clinical trials are involved, recruitment challenges increase. Some initial problems in recruitment of eligible women into the MOM's Project centered on two project criteria: the early gestation criterion (prior to 28 weeks of pregnancy) and the randomization process. Potential referral sources, not understanding the nature of a clinical trial, were resentful that their referrals could be rejected solely on the basis of gestational age. They viewed the project as a resource that should be open to all pregnant women in need. This initially caused considerable animosity in the community, leading to refusal to refer women. Providers especially resented the randomization process that failed to consider the women's diagnostic assessments.

After pregnant substance-using women are *found*, the challenge is to *engage* them into treatment. Women who are referred for an assessment often do not appear for appointments; women who are assessed may not enter treatment. In developing engagement strategies, it is important to

recognize the concerns of these women that may interfere with following through with assessment and treatment.

On their own, the women often are not able to recognize the multiple defense mechanisms of the disease of chemical dependence, so they continue to abuse alcohol and other drugs during pregnancy (Davis 1994). Some women have little or no contact with social services and health care agencies and are able to conceal their pregnancies until delivery. Other women fear the loss of their children to child protective services agencies (Streissguth and Giunta 1992, pp. 137-154). Many pregnant women fear prosecution if their drug use should come to the attention of any authority, especially the criminal justice system.

RECRUITMENT IN THE MOM'S PROJECT

By using results from focus groups of women in treatment, it was determined that reluctance to enter treatment had to do with denial of chemical dependence rather than concerns about research or randomization. Problems associated with participation in a clinical trial appeared to be related to community clinicians' attitudes and not the opinions of the pregnant women being recruited. Only 7 percent of recruited women refused their randomized assignments at enrollment.

Recruitment Strategies

To address recruitment challenges, public health nurses and social workers who were maternity case managers were selected as primary recruitment agents for two reasons: (1) to access referral from the parent agencies of these traditional social and health care services and (2) to capitalize on the history of these two disciplines in coordinating and linking service delivery, skills vital for working with the target population (Ridgely and Willenbring 1992, pp. 12-33).

Approximately 50 percent of case management time was spent on direct recruitment. Remaining time was spent on providing ongoing case management services to women enrolled in project treatment. Project case managers functioned in a manner similar to that of field-based caseworkers, a method that is the predecessor of many case management models (Schilling et al. 1988). The workers helped each woman identify her needs and the needs of her family and worked with her to ensure prenatal and postpartum medical care, maternity support services, and community social services such as safe housing, food, transportation, and child care. The provision of case management services was an additional incentive to a woman's ongoing participation in the project.

For example, one commodity in constant demand was safe, alcohol- and other drug-free affordable housing, which case managers helped locate for women participating in treatment.

Recruitment Sources

Early in the project, maternity case managers spent considerable time and energy identifying and "courting" personnel from traditional agencies for potential referrals. The list of agency recruitment sources for the project included 30 traditional agencies (e.g., jails, public health clinics, public assistance offices, child welfare agencies). The time was spent at agencies providing staff training, making presentations, observing characteristics of the client population, and maintaining personal contact with key personnel on a systematic basis. (However, referrals from some of these agencies failed to materialize regardless of the efforts of the project staff.)

The largest single referral source was women who self-referred (approximately 25 percent of all women who participated in the project). Many self-referred women most likely received initial information about the project from an established agency. Local public assistance offices, a constituent agency of the case manager social workers, referred consistently (about 19 percent). A most successful outreach effort was made to incarcerated women in the county jail facility. A social worker and public health nurse case management team visited the jail weekly to recruit new clients, which resulted in 16 percent of the approximately 19 percent referrals from the criminal justice system. Figure 1 shows a breakdown of recruitment sources.

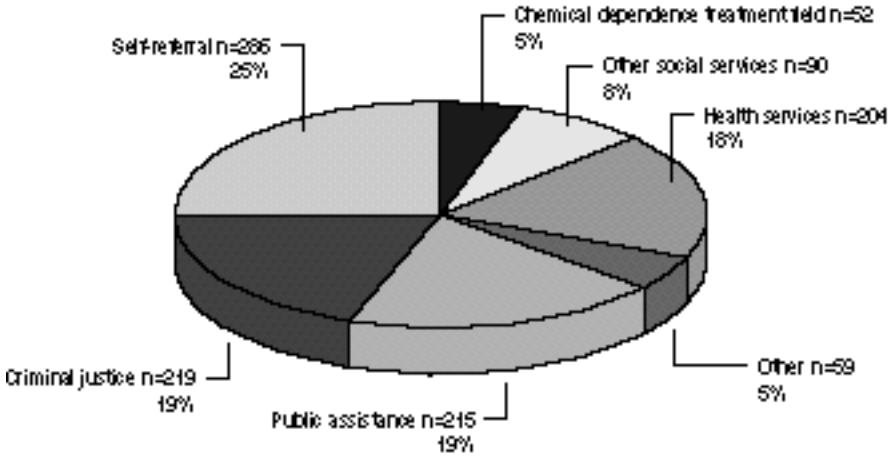

FIGURE 1. *Women recruited, by source (n=1,125)*

Client Characteristics

Women of color accounted for more than half of all referrals to the project (about 51 percent). More than a third of the referrals (approximately 35 percent) were African-American, about 9 percent were Native American, and slightly more than 3 percent were Hispanic. Caucasian women accounted for the other project referrals (approximately 49 percent). Figure 2 presents the ethnicities of the women recruited.

Case manager recruitment staff members quickly recognized that women who were eligible for the project presented problems as difficult as those of any clients with whom they had worked. Many of the women either lived on the streets or moved among friends on a regular basis. The women were "tuned in" to their addiction and used every resource available to satisfy it. Information from women who were eventually enrolled into the project (n=366) indicated that 89 percent were severely chemically dependent according to the *Diagnostic and Statistical Manual of Mental Disorders (Third Edition-Revised)* (American Psychiatric Association 1987). Seventy percent had at least one treatment experience before entering the MOM's Project, with almost one-third (32 percent) having participated in three or more prior treatment programs. A substantial majority (79 percent) reported having been incarcerated at least once, and 43 percent reported involvement with police before age 18. More than half the women with children (58 percent) had a history of involvement with child protective services.

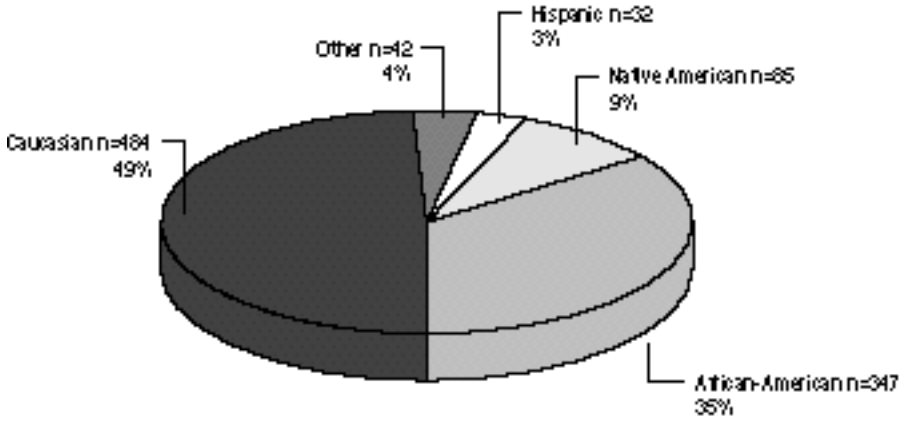

FIGURE 2. Women recruited, by ethnicity (n=990)

PROJECT RESPONSE TO RECRUITMENT COMPLICATIONS

To integrate the diverse agendas of recruitment agencies and other participating organizations, the project adopted a philosophy of recovery and emphasized the research context. MOM's Project treatment and community staff members adhered to a philosophy-of-recovery framework for working with the women in a multidisciplinary environment. In practice, this prevents the various treatment and support staff members from unintentionally interfering with the recovery process. This philosophy is resilient and focuses on solutions. Each woman's long-term goal is to reach her greatest potential as both an individual and a parent. The recovery process helps the woman evaluate herself by identifying her own strengths.

Under the recovery philosophy, the entire multidisciplinary staff practices giving positive feedback and role modeling. This allows clients to restructure their dysfunctional behavior patterns and practice positive interactions in a safe and empathetic environment. This philosophy led to the termination of individual project staff members who were unable to provide the demonstration services in a research context. Other project staff members were unable to prioritize recovery above individual agency agendas. The emphasis became *recruitment to chemical dependence treatment* as opposed to recruitment to other services being offered by the project, such as child care or prenatal care. This approach called for each project component to merge its agency and professional goals into the MOM's Project philosophy, with the focus on the client's long-term commitment to recovery. It became incumbent on the case managers, in their initial recruitment contacts with the women, to set the tone for this recovery milieu. The case managers focused on assisting clients to identify defense mechanisms that maintain denial, learn and reduce signs and symptoms of relapse, and reduce or eliminate destructive behavior patterns (Davis 1994).

To further minimize problems of diverse agendas, the project established standing committees to work on research- and demonstration-related issues and develop protocols and procedures for implementation. Each protocol and procedure was committed in writing in the *MOM's Project Implementation Manual* and the *MOM's Project Research Matrix* (LaFazia 1993*a*, 1993*b*). The implementation manual describes details for each demonstration component. The research matrix includes all research measures, timelines, and responsibilities for administering measures and tracking clients. These products were used to resolve conflicts, clarify roles, and serve as the final authority for each participating organization.

Midway through the project, a panel of outside experts was convened to assess recruitment efforts and provide recommendations for improvement. The panel included three researchers with at least 5 years of experience working with street-based drug users and two outreach workers who had worked with low-income pregnant women.

The panel members met with project staff members over several weeks and cooperatively identified the following barriers to increased enrollment:

- The parent agencies of the project's public health nurses and social worker case managers did not provide the anticipated number of referrals.

- Adolescents ages 16 and older were intended to be a major segment of the treatment population; however, few adolescents entered treatment.

- Recruitment as a priority appeared to be lost in a complicated maze of issues facing case managers and other project staff members.

- The potential for street-based and other more direct methods of recruitment had not been examined.

- Case managers made decisions concerning the focus of recruitment efforts without adequate information about the number of pregnant substance-using women an agency served.

- Case managers had limited information about agencies' attitudes toward treatment in general and the MOM's Project specifically.

- Case managers had varying and, in some cases, low levels of skill and knowledge about techniques for engaging substance-using women into treatment.

- Case managers appeared to be spending extensive time with some clients without engaging them into treatment.

Recruitment Enhancement

The project implemented the following five recruitment-specific activities: (1) A recruitment committee was formed to meet monthly to review recruitment activities and progress; (2) the recruitment protocol was enhanced to incorporate existing knowledge about treatment engagement techniques and limit the amount of time case managers spent on recruiting individual women; (3) a recruitment coordinator was hired to survey social services and health care providers, especially providers of services to

adolescents, assess the usefulness of direct recruitment, and otherwise strengthen the recruitment process; (4) other project staff members, especially those from the chemical dependence treatment program, were encouraged to become involved in recruitment efforts through providing ongoing presentations to health care and social services clinics and agencies; and (5) project staff members encouraged representatives of potential referral sources to visit the treatment facility.

Social Services and Health Care Providers Survey

A survey was conducted of the agencies on which the case managers were expending their recruitment efforts. The primary focus was on traditional health care and social services agencies. The survey focused on the time spent by case managers on those agencies and their referral rates. Discussions were held with agency personnel to assess the level of negative attitudes toward the project and to determine whether continued involvement would result in increased referrals. Based on the survey, it was determined that many of the traditional agencies targeted did not provide sufficient referrals to the project to warrant the time expended. Therefore, the outreach plan was revised, and the focus moved to nontraditional agencies (e.g., missions, needle-exchange locations, food banks). (Nontraditional agencies provide services to clients who do not access traditional social services and health care systems, such as very poor people and homeless substance-abusing people who live on the street. More than 25 nontraditional agencies were added to the agency recruitment list.)

The initial study design of the MOM's Project proposed that up to 40 percent of clients in the study would be pregnant adolescents. From the onset of the project, this population was difficult to recruit, engage, and enroll into the project. Although extensive effort was spent on adolescent services agencies, schools, and the juvenile justice system, adolescent referrals did not materialize. Youth care providers were surveyed to determine why adolescent referrals were not forthcoming and revealed the following: (1) Pregnant teens were hard to reach, and even providers who worked exclusively with teens had a hard time gaining access to them; (2) certain agencies receive supplemental funding to work with pregnant teens and thus were reluctant to refer teens to other programs; (3) teens, still early in their substance abuse, were better able to cease their alcohol and other drug use (at least temporarily) when they discovered that they were pregnant; and (4) agencies and teens did not identify substance abuse treatment as necessary.

Direct client recruitment often involves "working the streets." Street-based recruitment is more time consuming than agency recruitment.

Like most urban areas, Seattle-King County comprises a variety of geographic zones with differing population characteristics and drugs of choice. The characteristics of these zones can change over the course of a day (e.g., a downtown park frequented by homeless, chronic alcoholics during the day can become dominated by crack users at night), as well as over longer durations, and thus need to be monitored on a regular basis.

The recruitment coordinator spent time working the streets in each of the city's primary drug zones and in two major prostitution areas. The initial focus of these efforts was exclusively on pregnant women. Over time, the effort shifted to the goal of spreading the word about the project to men and nonpregnant women as well, in hopes that peer referrals would occur. These efforts succeeded in increasing project visibility and familiarity to street-based substance users. Time also was spent fielding requests for treatment by women ineligible for the project. Flyers routinely were placed in laundromats, beauty parlors, and neighborhood stores and on utility poles in neighborhoods with large concentrations of substance users.

The effort on direct client recruitment showed that such activity, although valuable for targeting women who are often invisible, was too costly in recruiting actual numbers. It was determined that time would be more effectively spent working with staff members from nontraditional agencies.

PROJECT RECRUITMENT PROTOCOL

By design, the project's designated recruitment teams of maternity case managers were not specialists in the substance abuse field. However, they received extensive training on substance abuse issues and shared client responsibility with the chemical dependence treatment staff. The enhanced recruitment protocol incorporated basic principles from field-based casework practice as well as from motivational interviewing for non-substance-abuse specialists (Rollnick and Bell 1991, pp. 203-213). A straightforward script was developed, giving prospective clients information and advice about the need to change their behavior. The case manager's role was to prepare women for a change in their drug lifestyle while emphasizing chemical dependence treatment as a necessary and available resource.

Although the project could not modify the recruitment criteria of early gestation and randomization, all the positive services available to the women were incorporated into the recruitment script. The benefits list was extensive and included referral to women-specific treatment for up to 12 months postpartum regardless of delivery status and custody (stillbirth, miscarriage, abortion, adoption, or foster care); opportunity for children

to be in residence with mothers; child care services while parents were in treatment; participation in research-related services that provided health care, social services, and child development assessments; gift certificates to a local department store for participation in research; assistance with financial and medical applications; and initiation of prenatal care through uninterrupted medicaid coverage (through 50 days after delivery for women at or below 185 percent of the Federal poverty level at the time of entry into care).

The recruitment script, including the benefits available, was presented in the context of a recovery approach. Rapport was established through gentle but firm confrontation with a woman regarding her drug-related issues, that is, other problems in her life that were connected to her substance use. The script included assuring the woman that chemical dependence is not *bad* or *wrong* but that it is a disease that progressively worsens and will continue to affect her life. She was reminded that regardless of her situation, she needed to start working on her recovery so that she could effectively handle the stresses in her life.

The enhanced recruitment script also established some time limits in working with each woman. The elusive behavior of some pregnant substance-using women often required an enormous amount of time to establish contact and build meaningful relationships. Initially, case managers spent considerable time working with a small number of resistant clients. Setting time and contact limits proved to be in the best interest of the chemically dependent pregnant women as well as beneficial to the case managers. When a woman is still enmeshed in denial, supportive persons tend to assume the role of enabler, which is counterproductive to recovery. The parameters for case management engagement activity included a limit of 1 month. If after a month the woman had been offered all the basic program services and still had not committed to a chemical dependence assessment, she was referred to the community for ongoing services, including referrals to community chemical dependence treatment agencies.

DISCUSSION AND CONCLUSIONS

The use of the public health nurse and social worker team as the project's primary recruiters proved to be effective in getting women into project or community treatment. The maternity case managers incorporated their expertise in working with difficult populations and their knowledge of community resources into a specialized advocacy role, working with women toward the primary goal of referral to chemical dependence treatment. Over the length of the project, more than 1,000 women were recruited, and 366 were enrolled in the project. Using maternity case

managers as recruiting agents was fiscally advantageous because, in Washington State, maternity outreach and case management is a billable medicaid expense. Programmatic advantages for replication stem from the availability of public health and public assistance social workers in every community throughout the State.

The largest age group recruited (approximately 34 percent) was 20 to 25 years of age; the second largest age group included women 26 to 30 years old (27 percent) (figure 3).

The majority of women recruited to the project were identified in either the first or second trimester of pregnancy (about 80 percent), with a large number recruited in the first trimester (approximately 38 percent) (figure 4).

In summer 1996 the MOM's Project will complete the evaluation of recruitment and admission to chemical dependence treatment (Lanz et al. 1995). Through the evolution of the project, it has become evident that case management may be an important link enabling women to successfully engage in treatment services. Further research is needed to explore the effect of case management services on the retention of pregnant substance-using women in treatment *and* on their transition back into the community.

The MOM's Project also is involved in a 3-year cost-effectiveness study funded by NIDA through the Boston-based Health Center for Economics Research. The study will examine the cost of various services received during pregnancy and after delivery for the project's treatment program. The cost-effectiveness of recruitment will be examined as part of the analysis.

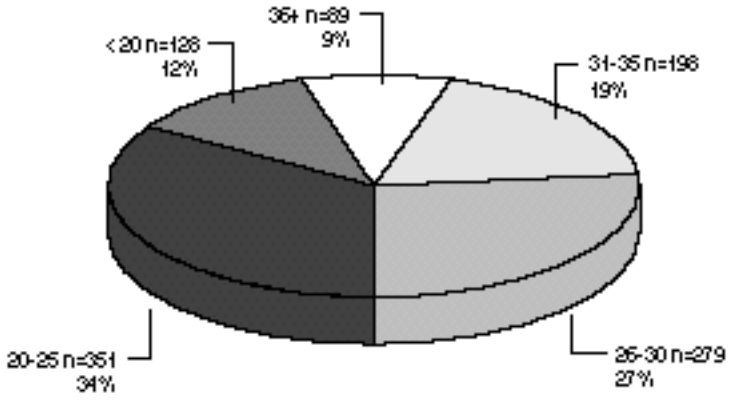

FIGURE 3. Women recruited, by age (n=1,045)

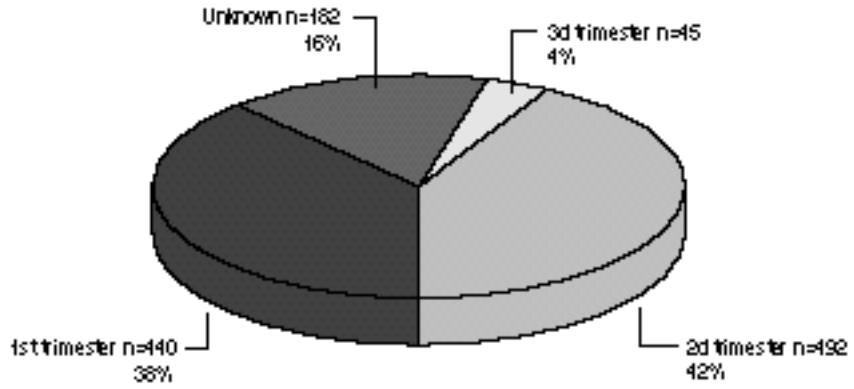

FIGURE 4. Women recruited, by trimester of pregnancy (n=1,159)

OUTREACH/RECRUITMENT/CASE MANAGEMENT VIGNETTES

The following are two descriptions of typical legal, social, and medical support advocacy efforts provided to substance-abusing pregnant women.

County Jail Outreach

Client Description. The client is a 22-year-old African-American woman, 5 months pregnant, and in jail at time of referral.

Client Needs. The client had no prenatal care prior to arrest, has no financial support, has no medical coverage, has been denied entry into the medicaid program because of her criminal justice status, and has a court hearing on criminal charges pending.

Outreach/Recruitment/Engagement. The referral came from jail health services. The case management team interviewed the client at the jail and facilitated resolution for medicaid coverage (through negotiations with the State office) and presented an argument to the court that the pregnant client and her 4-year-old child would best be served through treatment rather than further incarceration; the woman was enrolled for prenatal care.

Outcome. The client received an amended sentence, was randomized to a community substance abuse treatment program, participated in long-term residential treatment, delivered a healthy baby, returned to the community with her children, and remains in recovery.

Community Outreach

Client Description. The client is a 27-year-old pregnant Caucasian woman with two children, ages 5 and 6, who recently terminated a long-term violent relationship (including several hospitalizations). She is addicted to alcohol and cigarettes with occasional marijuana use, was raised in an alcoholic environment, has no high school diploma, has a low-wage employment history, and recently began a relationship with a nonabusive partner.

Client Needs. The client needed public assistance because of a breakup with an abusive partner, was served an eviction notice from her apartment (which cost $525 a month), was 5 months pregnant with no prenatal care and no extended family support, received threats from her ex-partner, and had no transportation to treatment and no child care for her children while in treatment.

Outreach/Recruitment/Engagement. The client was referred by a public assistance worker; she admitted chemical dependence problems but was overwhelmed with financial and housing crises and other problems that interfered with her getting into the treatment program. The focus was placed on activities to help her resolve her immediate housing and financial concerns so she could enter treatment. Case managers interceded with the landlord to help resolve the rental dispute, initiated referral to prenatal care, located child care so that the client could participate in treatment, provided counseling about domestic violence, and established a supportive role to assist her with other problems.

Outcome. The client entered MOM's Project outpatient treatment within 1 week of referral.

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ACKNOWLEDGMENTS

The services and research reported in this chapter were supported by NIDA grant R18-DA-06361 and by the State of Washington through the 1989 Omnibus Drug Act. A special acknowledgment is made to the pregnant women who overcame difficult obstacles to participate in the project.

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