Building Bridges: Treatment Research Partnerships in the Community

Ira J. Chasnoff, Paul R. Marques, Irma H. Strantz, James Farrow, and Shoni Davis

INTRODUCTION

Substance abuse during pregnancy continues to affect the lives of families across the United States. Most communities are not organized to deal with the multiple problems that must be addressed when developing intervention and treatment programs for pregnant women. At the same time, many citizens and community organizations may be suspicious of outside investigators stepping in to design outreach and treatment programs within existing structures and organizations. These difficulties are multiplied if the community regards the research as an opportunity to take advantage of the community without providing any long-term benefit to the community members.

There is little debate about the need for a wide-ranging assortment of services for indigent women who are involved with alcohol or other drugs. Rather, the debate revolves around how best to provide and assess comprehensive drug treatment services. The predominant issues of cost, convenience, and effectiveness inevitably have an effect on research. Centralized programs conducted at comprehensive health care facilities, such as a university medical center, provide a congenial environment wherein to conduct treatment services research but provide relatively little access to the populations at highest risk. By contrast, community-based providers with direct access to a sufficient number of clients have little or no experience in conducting or participating in clinical research projects and are less apt to buy into the values of the research culture or appreciate the need for objectivity and experimental control.

Nevertheless, overcoming the many difficulties associated with conducting research in a community setting is important—even essential—because the majority of service providers and consumers are found in the community. It is here that empirical evidence of program effectiveness must be found. For this reason, there are strong incentives to identify and overcome the obstacles to conducting a research project in the community milieu.

This chapter identifies some potential barriers to implementation of a community-based treatment research program. The issues described are derived from the experiences of four treatment research programs located

in four different parts of the country (i.e., Chicago, Illinois, Los Angeles, California, Landover, Maryland, and Seattle, Washington). Each project was established to develop, implement, and evaluate the effectiveness of a substance abuse treatment program for pregnant and postpartum women within a community setting in conjunction with a variety of services provided through State and local agencies.

PROGRAM IMPLEMENTATION

The NIMBY (Not In My Back Yard) syndrome is not unique to any one social, ethnic, racial, or economic group. In spite of the devastation wreaked on some communities by substance abuse, many neighborhoods are reluctant to allow drug treatment programs into the community. Although residents often view the substance abuser as a threat to community safety and as a harbinger of the deterioration of local values, the promise of the availability of treatment facilities does not alleviate these fears, and many community-based programs face an uphill battle in trying to find an appropriate location for service delivery.

The Chicago program, operated by the National Association for Perinatal Addiction Research and Education (NAPARE), is a community partnership that includes treatment providers, health care agencies, and community hospitals in an inner-city neighborhood on the near west side of the city. This community has some of the highest rates of substance abuse, murder, infant and child mortality, and violence in the metropolitan area; drug deals are openly consummated on most street corners. However, many residents banded together to protest the opening of a treatment program in the neighborhood and worked to block changes in zoning restrictions that would allow the facility to operate. It took several months of attending community meetings and working with local leaders even to open the doors of the building.

Gangs also threatened the existence of the program. In a related program developed to support the original treatment research project, NAPARE opened a Head Start program within a Chicago Housing Authority site. Unknown to the staff at the time of selecting the site, the housing unit sat on the border of two gangs' territories. While children were in class, gangs attacked the program classroom with gunfire, shot out windows, and broke into the classroom and threatened the children. These repeated attacks resulted in three shutdowns within a week's time. Negotiations with the gangs to declare the area a "gang-free zone" took up more precious time before the program could be implemented fully. These delays caused the late startup of recruitment and service provision and affected the number of patients recruited into the study in the first year of funding.

BUDGET CONSTRAINTS

Startup problems are the bane of treatment research programs, which typically have a lifespan of 3 to 5 years. Therefore, the design and management of a budget for treatment research often demand more care and scrutiny than a budget for service provision only. Reallocating funds from staff positions to facility or operating costs can have a critical effect on the number of research participants who can be enrolled in the study and exposed to the intervention. If the overall number of participants in the final database is too small, apparent changes occurring in certain study variables may fail to achieve statistical significance. Also, if the number of participants involved concurrently with the program is too small, with artificially low counselor caseloads and peer group memberships, any benefits derived from the treatment milieu may be impossible to replicate in other treatment settings.

A treatment research program's budget can be affected by the seemingly simple task of ensuring the safety of staff members and program participants. A treatment research project is almost always a large investment in terms of carefully selected and trained staff members, and rapid turnover is an anathema. Therefore, to secure staff members for a long period, obtaining an attractive and safe facility is a major priority. In addition, research participants, particularly mothers with infants and toddlers, are not likely to participate in a treatment program where the setting is dangerous. In recent months, new concerns for the safety of research participants and staff members in inner-city research projects have been caused by escalating violence in the communities. The researcher must deal with this new reality and include safety precautions (e.g., bulletproof windows, iron fences and gates, security guards, alarm systems) in the budget.

In the original plan for the Los Angeles program, the community-based agency was to house both the experimental and control groups at two leased sites in south-central Los Angeles. However, after the grant was funded, it was necessary to modify the budget to provide for more costly leased space, especially for the experimental group, and an armed security guard at each site. Because of these budget changes, counselor positions were lost, which greatly reduced the ongoing treatment capacity at each site. However, it was concluded that research participants could be enrolled and tracked, in both the experimental and control groups, in sufficient numbers to provide for outcome comparisons that could reach statistical significance. Also, although the number of treatment slots at each site was reduced, the low counselor-to-client ratios and small therapy group sizes in the enhanced intervention program were preserved.

(Nevertheless, it was decided to seek supplementary funding to restore lost treatment capacity.)

Finally, as the demonstration treatment research grant nears its end, a transition for financial support for the treatment services must be made to State and local sources. This requires a realistic look at the budget with close attention to obtaining funding from a variety of agencies. The community will have come to expect the wide range of services made available by the large infusion of Federal funds that supported the treatment research, but few States or communities will be able to support that level of commitment over the long term. If the program ends at the conclusion of Federal funding, the community will have an even greater reluctance to welcoming the next treatment research program.

IMPLEMENTING THE RESEARCH PROTOCOL

When a study protocol is to be made part of a service delivery program at an existing community agency, its introduction can be facilitated if it is not viewed as a special case or as an activity of no lasting value to the organization's mission. For any new treatment program to be effective, the management and clinical staff members must understand and endorse its goals and philosophy and feel comfortable with their respective roles. Also, when a change in program content is being considered, there must be opportunities for staff members to provide input on the change to encourage a feeling of ownership and commitment. Therefore, all components of the program (e.g., relapse prevention, psychosocial and parenting education, mother-infant bonding activities), as well as the research instruments and schedule, should be developed or reviewed and accepted by a committee that includes members of the agency's drug treatment clinical and management staffs. By involving key drug treatment management and clinical staff members in each step of this process, some stereotypical, negative attitudes toward the research participants and the rich program of services and activities planned for them can be neutralized.

From the outset, the Los Angeles researchers felt that there must be an underlying consistency with the existing community treatment system so that staff members in the new program would not be placed under great stress in the work environment. The community agency involved in the research project had used three of the components of the experimental treatment program (i.e., Rawson's relapse prevention model [Rawson et al. 1990] for cocaine abusers, parent education, 12-step Narcotics Anonymous groups) at two other treatment sites. However, staff members with the most experience with and understanding of these approaches were

not available to help implement the new program because they had been transferred to other positions. In every human services system, experienced clinical staff members are routinely transferred or promoted in support of organization priorities. Therefore, it was determined that new personnel would be recruited and trained specifically for the day treatment program.

INFORMATION OWNERSHIP

Community-based treatment programs operate under a different set of priorities than those for university-based programs, especially with regard to the acquisition and use of information. From a research perspective, data are collected over a long period with only occasional delving into the database to evaluate progress and assess preliminary information. Treatment program personnel often want a more rapid turnaround of information, which may result in overinterpretation or premature use of data. In addition, if a research team uncovers information that could have implications for the treatment approach for a specific research participant, the question arises whether the researchers are responsible for reporting that information to the woman's therapist. This is an issue that frequently arose during the intensive individual interviews that were conducted as part of the research assessment of the women in the Chicago program. Clear guidelines for communication between the research and clinical teams were explained at the beginning of the project, and the working relationship between the two teams was under constant scrutiny throughout the term of the project.

TREATMENT SITE STAFFING

There are many benefits in collaborating with an established agency for the treatment intervention aspect of the study. In the Los Angeles study, as provided for by the grant, the University of Southern California contracted with a community-based agency to provide the specified drug treatment services to research participants. The agency, which was established soon after the 1965 Watts riot, provides a range of medical, public health, and substance abuse services to residents of south-central Los Angeles. At least three benefits resulted from the involvement of this agency in the collaborative treatment research effort.

1. Among key agency staff members, there existed a body of knowledge and experience in the delivery of drug treatment services, including those that target pregnant and parenting women; thus, program implementation was not a trial-and-error activity.

2. Through the community-based agency, a variety of medical, public health, and mental health services were made readily accessible to the research participants and their infants and families.

3. African-American community leaders and agency staff members were involved in treatment research in a way that was positive and brought new services to the community. Furthermore, the agency was known and accepted by the research participants, which avoided any potential biases related to client refusal to participate because of suspicion regarding the motives of the treatment provider.

However, established agencies have standardized job descriptions, salary schedules, hiring policies, and procedures, and various management reviews and approvals must be obtained before any personnel action can be taken. On the one hand, when many systems are already in place, it is easier to implement a new program in collaboration with an established agency. On the other hand, if the research program has personnel requirements that differ from the agency standard, much time can be lost in the review and approval process. For example, it often was found by all four research teams that although the counselor positions in the research protocol had duties and caseload standards different from those of the regular positions, it seemed easier to use existing personnel than hire new employees.

A frequent difficulty in staffing treatment research programs is retention of staff. It is well known that supervisory and line staff workers are seriously underpaid in most publicly funded drug treatment programs. Even if a research grant budget can support higher salaries for supervisory and line staff workers at research sites, the community agency’s salary schedule for drug treatment personnel usually cannot. Therefore, new staff members, hired and trained specifically for the research treatment program, are soon receiving job offers from agencies that value the expertise they have gained from working at the research site and can afford to pay higher salaries.

Skilled counselors, regardless of ethnic or demographic mix, are sometimes difficult to find, especially those willing to work for the wages available in the communities served by the research treatment program. If this difficulty can be anticipated and there is adequate lead time to set up the program, it is wise to fully evaluate the counseling skills and backgrounds of direct services providers. Certification standards are not rigorous for drug treatment services providers, and even fully certified providers may not have experience with women on welfare and their particular problems. For example, without significant training and preparation, people with experience in working in a middle-class 12-step program cannot be transplanted usefully to a milieu of urban poverty.

COLLABORATION IN SUBJECT REFERRALS

The university-based researcher who engages in a study that involves one or more independent community organizations must understand and accept the fact that, even with general oversight responsibilities for the study, he or she is perceived as an "outsider" by each organization's staff. Therefore, the researcher needs to have "friends in high places," such as one or more key managers of the agency who support the research goals and will keep the researcher apprised of any organizational changes that might affect the research. The importance of this connection was demonstrated vividly in the Los Angeles study, where researchers depended on a collaborating agency for client referrals; they unexpectedly lost key manager support at the agency together with the promised flow of referrals.

Unlike research in which investigators recruit research participants from a large pool of their service recipients, the women in the Los Angeles drug treatment study were drawn from the child protective services agency's caseloads. After being identified and reported to the agency at the time of delivery as probable drug abusers because of certain behavioral and physical indicators that they and their newborns exhibited, including a positive toxicology screen, the mothers were assessed further by agency workers. It was first determined whether there was endangerment to the infant if he or she was not placed with a relative or in foster care and then whether the mother would agree to complete a drug treatment program. If treatment was indicated, the worker referred the mother to this treatment research project or to another treatment program.

Soon after being notified about the funding of this research proposal, the investigators in Los Angeles learned that there had been certain organizational changes in the child protective services agency. The clinical policy and management staff members who had helped design the program had been transferred to other positions within the agency, and their firsthand knowledge of study objectives and special commitment to the project were lost. The agency also hired a new director who reorganized the agency and established new regions, with the result that many new teams were handling the south-central Los Angeles target area.

Although hospital reporting of drug-exposed infants remained constant during the period following the implementation of the Los Angeles project and a steady flow of referrals was expected from the agency, by the end of the sixth month of operation, the number of referrals was falling far short of expectations; only one-sixth the projected number of research participants were referred by child protective services workers. Thus, to increase referrals, there was an urgent need for researchers to establish new relationships with the management and line staffs at the agency.

A program of outreach and inservice orientation was developed and delivered by the researchers and program staff personnel to workers in the new regional offices.

When initiating, developing, and expanding a referral network from existing public services, it is not always clear which egos need to be stroked or whose indulgences need to be sought to gain full cooperation. In the Landover program, despite having acquired all the relevant letters of assurance from the hospital's chief executive officer and medical department chairpersons, researchers found that the hospital operations officer had the authority and inclination to prevent the smooth implementation of a referral system by initially allowing staff nurses to do no more than pass out brochures to prospective clients (mothers who tested postive for cocaine at delivery). Under this peculiar policy, the mother would have to initiate a telephone call to project personnel. This was an impossible way to form a sample, but it was an easy barrier to erect and to justify in the interest of patient confidentiality. This clash seemed related more to a turf problem or concerns about hospital image than to protection of confidentiality, but the motive never became completely clear. One neonatologist explained that any publicity that associated the hospital with area drug problems would have made it more difficult for operations personnel to implement their plans to build a new thoracic surgery center. On the other hand, the hospital had an ethical responsibility (and legal incentive) to protect patient confidentiality, and the operations department may have been genuinely motivated by such concerns. If this was the true motive, this particular type of barrier may have represented a case where assiduous risk control led to *greater* risk for mothers and their children (preventing access to remedial services) than would have occurred from a more measured degree of protection.

This barrier was eventually circumvented by repeated visits with direct services providers in the hospital. Caregivers (social workers, midwives, nurses), who have a more personal understanding of this population and are the key personnel who can make or break a referral process, must be convinced of the value of a research program. Administrative and operations personnel have to be involved in setting up the program, but their agendas should not be allowed to become barriers to the project goals. It is also important to have multiple referral sources so that difficulty with any one source does not have the potential to shut down a project.

RANDOM ASSIGNMENT AND COMPARISON GROUPS

Caregivers are often hesitant to make referrals to treatment research programs that plan to randomly assign some referrals to comparison groups,

so this topic should be approached with care. In the Landover project, it did not matter that the women in the comparison group were informed explicitly that they were free to take advantage of any public remediation services that would ordinarily be available to them independent of the research program. A great deal of "sales and marketing" by researchers was required to overcome resistance from referring providers. This involved chatting, informing, and yielding when necessary. Some tactics included hosting an open house for caregivers, soliciting their advice about gifts to be included in "goodies" bags provided to women (e.g., diapers, thermometers, coupons, etc.), providing inservice presentations, and sending periodic newsletters to keep the referral community informed.

In addition, any evidence of the investigator's humanity that can be shown while engaging interest in and attention to the research project can help. The investigator should make it clear that even the comparison group of women will be better off in some way for having been involved in the project. In Landover the investigators conceded the need to provide case management services (but not direct treatment) to the comparison group as an incentive for cooperation, and this concession helped overcome the reluctance of caregivers to make referrals.

Comparison groups should be studied carefully to log the extent of their involvement with nonproject-related supportive or treatment services and with outside resource people who play a role during the project period. This is always important in treatment research but may be particularly important with indigent mothers whose initial needs are often more basic than their need for drug treatment. Mothers often benefit as much from help with the practical aspects of living as from targeted drug treatment. In many cases, treatment may be premature because a sizable proportion of mothers will have little incentive to value treatment. That is, for many (or most) there are no expectations of a better life, no employer threats, no spousal threats, no legal threats, and surprisingly, only a rare possibility of action by child protective services (likely because of system overload [Ashery 1992, pp. 383-394]). As a consequence, relatively few women who go to "drug treatment" are ready for treatment, and therefore, comparison groups that receive case management services have a good chance to do almost as well as the treatment groups. Placing more attention on measuring nontreatment support activities helps identify multiple other factors that may account for outcome differences between groups.

Finally, alcohol- and other drug-free comparison groups should be screened carefully for substance use and abuse. In the Chicago program, 19 percent of the pregnant women who volunteered to serve as drug-free controls for the study subsequently had a positive urinalysis for an illegal drug and had to be removed from the comparison group.

PROVIDING TRANSPORTATION AND CLINIC-BASED CHILD CARE

No project aspiring to conduct outpatient treatment research on indigent drug-involved mothers can avoid contending with the double dilemma of providing transportation and clinic-based child care. A large institution with a car or van pool or a child care facility is apt to have less trouble than a community-based startup facility. However, for any research project—regardless of equipment or resources—getting mothers and children to leave home and contend with rigid schedules and urban transportation delays is difficult. However, because structure and punctuality are important parts of drug treatment, these barriers must be overcome. In Chicago and Landover, a portable cellular telephone used for making one or more calls in transit (to women who had telephones) improved the likelihood of participants being ready when the van arrived.

Most treatment programs develop a transportation plan by eliminating unacceptable and unworkable alternatives. At first, in the spirit of making use of existing resources, it frequently seems sensible to work with either public transportation or an existing business—such as a ride service or taxicab company with a fleet of cars and drivers—to deliver groups of mothers to treatment services. However, it often becomes clear that public transportation is too inflexible and is a clear disincentive for mothers whose ability to plan and follow through is not great. The cost of working through private businesses that provide ride services is usually unacceptably high. In addition, neither public transportation nor private ride services provide the sort of personal contact opportunity with the clients that a project employee or driver can deliver. A driver has the opportunity to be a surrogate friend or social worker and often can be called on to help a mother with minor chores. The Chicago and Landover research projects found that employing their own drivers was a better solution.

In terms of using a van, the most economical method was leasing a van for the duration of the project. For the Chicago and Landover projects, leasing costs for a passenger van appeared reasonable, but no lending institution would accept the risk of being the owner of record of the van unless it was protected by a $1- to $2-million insurance liability policy because, in the event of an accident, a passenger might choose to file a claim against the owner. Although understandable from a financial perspective, insurance-motivated self-protection can complicate the establishment of community programs. The least costly alternative for the programs was to purchase a used van. Insurance was still a problem, and innovative approaches to acquiring insurance were used. The Landover project was able to acquire an insurance policy only from the State-assigned risk pool (even though

there had been no claim against any vehicle insured by the program). Annual insurance costs from that pool have been approximately $4,000. This is approximately half the cost of insurance had the program leased a van but nearly five times greater than a regular policy without the unusual passenger liability requirements.

Providing child care to study participants presents a different type of problem. As seen across the Perinatal-20 projects, mothers had from one to eight children, with an average of three. Although many more programs have become available, only a few treatment programs are geared to accept children while a mother is receiving outpatient services. In addition to routine child care requirements, seasonal difficulties must be anticipated and planned for. One child care resource is generally adequate for pre-school-age children, but summertime brings new burdens for keeping groups intact and caring for older school-age children. There are no easy solutions, but communities may wish to consider coordinating child care services with local parks and recreation departments and libraries.

To develop onsite child care services, a program must consider the serious issue of licensing the child care facility. Most treatment programs do not have the space required, usually the first floor, for a licensed child care area. Sunlight, outdoor play area, fire regulations, and evacuation routes are all issues that arise in most State licensing plans. In some States, if the mother is in the same building, licensing is not required, but the program faces significant liability risks if the mother leaves the building.

DELIVERING HOME-BASED SERVICES

Clinical case managers and research personnel associated with the treatment program may be required to visit some of the most dangerous and violent neighborhoods in any urban area. Personal safety is thus an issue. In setting up the Landover project, the senior case manager and project coordinator solicited advice from social workers and local police who were familiar with the area. The advice and experience they received generally served them well and were useful for other high-risk communities.

The first home visit involves the most uncertainty, and case managers go out in pairs on the first visit. Ordinarily, the case manager has spoken only on the telephone with a woman prior to the visit. But for any home visit, the primary rule is always, “Don’t take risks, and don’t be too conspicuous.” From this rule, the case managers have derived secondary rules. Most rules have been developed from experience in home visits and adopted to minimize the sense of danger. Some of these rules are:

- The streets are safest before noon.
- Be more cautious when there is no evidence of care given to the outside home environment.
- Back off when a prospective client is hostile or uninterested.
- Back off when there are many other people in an apartment; schedule another time or meet in a neutral place.
- Be cautious in hallways where people are loitering or when urine smells fill the air.
- Be more cautious approaching apartments than single-family homes.
- Do not wear jewelry.
- Keep a purse out of sight.

The Landover program had three robberies in 2 years, all of which occurred when the case managers became comfortable with the environments they were working in and relaxed their usual caution. Two of these incidents involved theft of money from purses (one with a threat of violence), and one was a forced entry and theft of a cellular telephone absentmindedly left in plain view in a van.

PROGRAM EVALUATION AND SUBJECT ASSESSMENT

When engaging in complex intervention research, particularly when several independent agencies are involved, it is helpful to conduct a process or formative evaluation and share the findings and recommendations with the collaborators. There should be a response to each finding by the researchers. After the first 6 months of the Los Angeles study, the investigators conducted a formative evaluation to determine whether the treatment program and research protocol had been implemented as intended and what system problems were being encountered by the collaborating agency staff members.

Feedback from child protective services workers helped explain the low number of referrals of women into the program at that point; the reasons fell into four major categories.

1. There was a lack of knowledge among certain agency divisions regarding the services available through the project.

2. There was disappointment that onsite child day care for infants and siblings was not available.

3. Because a new departmental policy permitted each client a choice of agency for mandated drug treatment, potential research participants were selecting other programs that were less demanding of their time and effort (i.e., once-a-week counseling).

4. Some workers in the high-risk agency divisions disliked the research project's random assignment process.

Child protective services staff members in the last category felt that they should be the ones to make the assignment to the day treatment program (experimental group) or regular outpatient services (control group) on the basis of their clinical assessment of client needs.

In response to the formative evaluation findings, the researchers and the collaborating agencies took the following steps:

- Outreach efforts were expanded to all child protective services workers in the key district offices.

- The drug treatment agency's parent organization applied for and received State funding to establish a child day care program in the area, with priority access for children of research participants.

- Management staff members in the district offices took a strong proactive stance regarding the research project and its comprehensive treatment services, whether provided in the experimental or control group setting.

It is imperative that researchers maintain an effective communication network with each collaborating agency, using both formal and informal means. Through periodic meetings, progress reports can be shared and system problems addressed. Through informal contacts, small problems and complaints can be handled. Because it was learned, through informal channels, that three of the key Los Angeles child protective services offices were being used as training sites for new workers, the researchers accepted the fact that the regular provision of outreach and educational activities in these offices would be needed indefinitely.

Finally, a researcher may need to call on top leadership in the collaborating agency to focus sufficient attention and effort on a major problem, such as casefinding. This may be difficult when a large bureaucracy is involved and the treatment program effort is the first joint venture in community research; it is easier when there is a history of mutually beneficial

collaborative efforts. In the Los Angeles project, the resistance of certain child protective services workers to referring their clients to a project with random treatment assignments could not be handled solely through education and marketing. The agency's director was invited to visit the treatment research site and was impressed with the drug treatment programs provided by the community-based agency. Because of concern about the potential loss of both important research and services to the community, the director, with the assistance of the administrative staff, became personally involved in setting monthly referral goals and raising caseworker awareness of the benefits of the program to their clients.

CONCLUSIONS

A critical need in collaborative studies is strong centralized oversight of all aspects of the project. Although this type of management is time consuming, it is too important for the principal investigator to delegate the responsibility to someone else. When the researcher is an outsider, the importance of tact, persistence, and the ability to establish and maintain good interpersonal relations cannot be overstated. Close monitoring of the referral and intake systems and the treatment intervention process may not appear to be related to research supervision, but the integrity and continuity of the program as designed and the validity of the outcome data depend on this type of ongoing review.

The extra effort is worth it. Changing drug use behavior in the community where a woman lives is theoretically more effective for individuals and logically more defensible for communities. Studies in both animal models (Siegel 1983, pp. 207-246) and humans (Robins 1974) have shown that the environment where dependent drug use develops has strong eliciting power over drug-seeking behavior. Plucking a dependent user out of that environment and providing treatment does little to permanently break the associative links that control the craving for drugs. Building relapse prevention skills within the community context is important. In addition, if everyone needing drug treatment services were removed from the community, then the community would not benefit from a climate of change and renewal. Conceivably, a drug-involved community may reinforce drug-using behaviors for others in that milieu. Logically, as one wave of drug-dependent people moves out, the next wave would be ready to move in. Thus, despite the difficulties of making change in the context of the community, there are ample incentives to overcoming barriers to treatment research and establishing strong service links among providers.

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AUTHORS

Ira J. Chasnoff, M.D.
President and Medical Director
National Association for Perinatal Addiction, Research, and Education
Professor of Clinical Pediatrics
University of Illinois
200 North Michigan Avenue, Suite 300
Chicago, IL 60611
(312) 541-1272 (Tel)
(312) 541-1271 (Fax)
7115.1134@compuserv.com (Internet)

Paul R. Marques, Ph.D.
Director
Drug Research Programs
National Public Services Research Institute
8201 Corporate Drive, Suite 220
Landover, MD 20785
(301) 731-9891, ext. 102 (Tel)
(301) 731-6649 (Fax)
marques@pire.org (Internet)

Irma H. Strantz, Dr.P.H.
Associate Professor of Research
University of Southern California School of Social Work
University Park Campus
Los Angeles, CA 90089-0411
(213) 740-3469 (Tel)
(213) 740-9832 (Fax)
strantz@bcf.usc.edu (Internet)

James Farrow, M.D.
Associate Professor
Medicine and Pediatrics
Director
Division of Adolescent Medicine
University of Washington
CDMRC Building
1959 Northeast Pacific Avenue
Seattle, WA 98195
(206) 685-1273 (Tel)
(206) 543-5771 (Fax)
jaf@u.washington.edu (Internet)

Shoni Davis, D.N.Sc., R.N.
Executive Director
Perinatal Treatment Services
Affiliate Assistant Professor
Department of Psychosocial Nursing
University of Washington
CDMRC Building
1959 Northeast Pacific Avenue
Seattle, WA 98195
(206) 223-1300 (Tel)
(206) 223-1279 (Fax)

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