

Improving Treatment for Drug-Exposed Infants Treatment Improvement Protocol (TIP) Series 5

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The opinions expressed herein are the views of the consensus panel participants and do not reflect the official position of CSAT or any other part of the U.S. Department of Health and Human Services (DHHS). No official support or endorsement of CSAT or DHHS is intended or should be inferred. The guidelines proffered in this document should not be considered as substitutes for individualized patient care and treatment decisions.

What Is A TIP?

CSAT Treatment Improvement Protocols (TIPs) are prepared by the Quality Assurance and Evaluation Branch to facilitate the transfer of state-of-the-art protocols and guidelines for the treatment of alcohol and other drug (AOD) abuse from acknowledged clinical, research, and administrative experts to the Nation's AOD abuse treatment resources.

The dissemination of a TIP is the last step in a process that begins with the recommendation of an AOD abuse problem area for consideration by a panel of experts. These include clinicians, researchers, and program managers, as well as professionals in such related fields as social services or criminal justice.

Once a topic has been selected, CSAT creates a Federal resource panel, with members from pertinent Federal agencies and national organizations, to review the state of the art in treatment and program management in the area selected. Recommendations from this Federal panel are then transmitted to the members of a second group, which consists of non-Federal experts who are intimately familiar with the topic. This group, known as a non-Federal consensus panel, meets for about three days, makes recommendations, defines protocols, and arrives at agreement on protocols. Its members represent AOD abuse treatment programs, hospitals, community health centers, counseling programs, criminal justice and child welfare agencies, and private practitioners. A chair for the panel is charged with responsibility for ensuring that the resulting protocol reflects true group consensus.

The next step is a review of the proposed guidelines and protocol by a third group whose members serve as expert field reviewers. Once their recommendations and responses have been reviewed, the chair approves the document for publication. The result is a TIP reflecting the actual state of the art of AOD abuse treatment in public and private programs recognized for their provision of high quality and innovative AOD abuse treatment.

This TIP, on the treatment of drug-exposed infants, is the fifth published by CSAT since a treatment improvement initiative began. It represents another step by CSAT toward its goal of bringing national leadership to bear in the effort to improve AOD abuse treatment.

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Chapter 1 - Introduction

What is Covered in this TIP?

The primary focus of this Treatment Improvement Protocol (TIP) is the *in utero* exposure of infants to illicit drugs. *In utero* exposure to cocaine and opiates, especially heroin, is highlighted, and there is a brief discussion of methadone. Although the substantial crisis of *in utero* exposure to alcohol is discussed, it is not the focal concern of this TIP. In addition, this TIP highlights medical and psychosocial services for drug-exposed infants *up to 18 months of age* and their families. Concerns regarding older toddlers and children are mentioned, but they are not the TIP's focus.

This chapter discusses the overall problem of drug-exposed infants and their families. The topics of chapters 2 through 6, respectively, are: medical management, followup and aftercare, psychosocial services, ethical and legal guidelines, and quality assurance. A summary of each chapter is provided at the end of this Introduction.

At the conclusion of these five chapters is an extensive bibliography that includes a significant list of references on *in utero* exposure to alcohol. There are also several appendices, including resources for parents and caregivers, a description of sample programs throughout the country for substance-using women and their children, urine toxicology guidelines, and a glossary of medical terms. Finally, there is an appendix on cost factors in the treatment of drug-exposed infants.

A number of important topics related to drug-exposed infants are not discussed in this TIP. For example, the HIV epidemic and its relationship to drug-exposed infants and substance-using mothers are not highlighted, but are referred to throughout the document. A future TIP on HIV and alcohol and other drug (AOD) use and abuse is forthcoming. As this TIP was being published, the Department of Health and Human Services issued new regulations regarding Substance Abuse Prevention and Treatment Block Grants. The regulations have many provisions relating to AOD treatment services for pregnant women and women with dependent children. Although these regulations are mentioned in this text, their relevance to the care of drug-exposed infants is not examined in depth.

The problem of AOD use and incarcerated women is not discussed herein. Nonetheless, questions are being raised regarding care for pregnant incarcerated women as well as drug-exposed infants whose biological mothers remain incarcerated. However, many of the sample programs listed in [Appendix B](#) have expertise in serving these women and children.

The Impact of Drug Exposure on Infants

The effects of drug exposure on infants are fairly well documented, and are fully described in [Chapter 2](#). General effects of drug exposure include intrauterine growth retardation, prematurity, neurobehavioral and neurophysiological dysfunction, birth defects, infections, and other effects. The neonatal abstinence syndrome - a complex phenomenon involving numerous systems - affects 60 to 80 percent of opiate-exposed infants. In addition to opiate-exposed pregnancies, inner-city hospitals are coping with a frightening rise in cocaine-exposed pregnancies. Cocaine-related effects include neurobehavioral dysfunction, cardiovascular problems in mother and fetus, spontaneous abortion and fetal compromise, vascular disruptions, and increased risk for infectious diseases, especially sexually transmitted diseases, including human immunodeficiency virus (HIV) ([Bandstra and Burkett, 1991](#)).

Not all drug-exposed infants are affected to the same degree. At one end of the spectrum are severely ill preterm or term infants requiring days or weeks of intensive care; at the other end are apparently healthy term babies with no obvious effects.

The effects of drug exposure may persist beyond the immediate neonatal period:

- **Effects of Opiates** - In some newborns, significant symptoms of neonatal abstinence were delayed up to 1 month ([Kandall and Gartner, 1974](#)). Epidemiologic data suggest a link between maternal opiate use and sudden infant death syndrome (SIDS) ([Kandall and Gaines, 1991](#)). A fairly early (1973) study of the growth and development of heroin-exposed infants (aged 3 to 34 months) found that 80 percent had signs of neonatal withdrawal and 60 percent had subacute withdrawal signs for the first 3 to 6 months of life. Half of the infants observed for a year or longer had behavioral disturbances (hyperactivity, brief attention span, temper outbursts). In some infants, growth disturbance was associated with behavioral disturbance ([Wilson, Desmond, and Verniaud, 1973](#)).
- **Effects of Cocaine** - Little information is available on the long-term results of cocaine exposure of infants. Chasnoff et al. (1992) found that cocaine exposure is a predictor of smaller head circumference than normal, which, in turn, is associated with slightly lower than normal scores on standard developmental tests. Cocaine exposure has been suspected of interfering with children's memory, auditory functioning, attention, cognitive performance, verbal and sensory skills, and academic readiness ([Khalsa and Gfroerer, 1991](#)). Studies have also shown however that scores of children exposed to cocaine *in utero* were born in the normal range. A number of experts voice objections to the "media hype" surrounding cocaine-exposed babies, warning that exaggerated reports of long-term effects could lead society to regard such children as a lost cause. These experts stress the value of early intervention in offsetting the effects of exposure and other environmental disadvantages ([Mayes et al., 1992](#); [Zuckerman and Frank, 1992](#)).

The long-term outcome of prenatal substance exposure is unknown. Studies to date have not controlled for the amount, intensity, or frequency of drug use, nor for the type of drug used and when it was used during the pregnancy. As with immediate effects on newborns, long-term effects on older children are expected to vary; some children will show few symptoms once drugs have left their systems, while others may experience more lasting effects ([GAO, 1990](#)).

Although drug exposure may be implicated in poor developmental outcome, it is by no means the only culprit. "Few studies have attempted to separate the impact of the drug from the effects of demographic and environmental risk factors. Of particular concern are potentially confounding variables such as low socioeconomic status (SES), poor nutrition, lack of prenatal care, ethnicity, family instability, caretaker dysfunction, multiple caregivers, family violence, and homelessness." ([Scott, Urbano, and Boussy, 1991](#)). Polydrug use is also a major concern.

Mothers and Families

For a substance-using mother, the birth of a drug-exposed infant is both a crisis and an opportunity. The mother - and the father, too, in many instances - often feels an overwhelming sense of guilt about the baby's condition. Cocaine-exposed babies may be lethargic, unresponsive, and disorganized in sleeping and feeding. When awake, they can be easily overstimulated and are often irritable. Such characteristics make parent-infant interaction difficult and unrewarding, and can lead parents to frustration, detachment, and avoidance. The stressful environment of substance-abusing women often includes physical or sexual abuse, single parenthood in a setting of maternal drug-use, and limited social support; these factors are profoundly detrimental to their parenting ability. Many such mothers are themselves victims of poor parenting, lack information on characteristic infant behaviors, and have unrealistic expectations about the abilities of babies and children (Freier, Griffith, and Chasnoff, 1991). On the other hand, the baby's birth may give the mother as well as the father the most powerful motive possible to undergo treatment and seek recovery. Interventions during the postnatal period must combine the goals of helping the mother abstain from drug use and assisting her with other complex social needs. Paramount among these needs is assistance in successful parenting. If possible, interventions with the father should also take place during the postnatal period.

Health Services and Cost Of Care

The cost of caring for drug-exposed infants is enormous, whether measured by the day, the neonatal treatment episode, or the entire spectrum of interventions during infancy and early childhood. A hospital in Los Angeles reported that the per-day cost of caring for a drug-exposed infant in a neonatal intensive care unit ranges from \$750 for a mild case to \$1,768 for a severely affected infant (*New York Times*, December 24, 1991). Total hospitalization charges in the newborn period are notably higher for drug-exposed than for unexposed infants. Phibbs et al. (1991) examined the added neonatal cost and length of hospital stay associated with fetal cocaine exposure among 355 infants born at Harlem Hospital in New York City. These investigators found that neonatal hospital costs were \$5,200 more for cocaine-exposed infants than for unexposed infants (\$7,957 vs. \$1,226). Crack cocaine exposure resulted in even greater cost, as did exposure to other illicit substances in addition to cocaine. Projecting their findings to the national level, the authors estimate that these costs would total nearly \$500 million. The GAO (1990) studied a small sample of hospitals and found hospital charges were up to four times higher for drug-exposed infants than for unexposed infants. One hospital had a median charge of \$5,500 for a drug-exposed infant vs. \$1,400 for an unexposed infant. In its limited sample of hospitals, GAO also found an extremely wide range of costs for treatment of drug-exposed infants, from a low of \$455 to a high of \$65,325. In Florida, caring for a cohort of 17,500 cocaine-exposed babies born in 1987 - including the costs of maintaining nurseries, intensive care units, and special education and intervention programs - will have cost an estimated \$700 million by the time the children enter kindergarten (*New York Times*, May 14, 1989).

Appendix G includes an in-depth cost analysis of the medical management of drug-exposed infants. Cost factors are evaluated with regard to: 1) evaluation and management services, 2) clinical procedures, and 3) pathology and laboratory tests.

Social Services

Drug-exposed infants and their families require a wide array of social services and impel new alliances among diverse agencies and providers. Drug abuse treatment and supportive services for the mother are immediate needs, as are followup and aftercare services for the newborn. A major goal of social services is to keep the family unit intact. Unfortunately, drug-exposed infants often end up being separated from their mothers, even if temporarily. Nationwide, the demand for foster care increased by 29 percent from 1986 to 1990; much of this increase is attributable to parental substance abuse. In 1990, New York City estimated that 57 percent of its children in foster care came from drug-abusing families.

Increase in foster care placements of children under 2 years of age has also been drastic; in Massachusetts, the number of children under 2 years admitted to foster care increased 73 percent between 1988 and 1990, while in Illinois, infants under 1 year of age admitted to foster care increased by 284 percent during 1985 through 1989 (GAO, 1990). An already overburdened system must gear itself to locating foster families that will

accept drug-exposed children, ensure the quality of foster homes, and provide extensive support to foster families.

Legal Systems

During the last few years, attempts to institute criminal charges against women who give birth to drug-exposed infants have increased. In a similar vein, some judges have sentenced pregnant drug addicts charged with unrelated crimes to prison to protect fetuses from further drug exposure. In some jurisdictions, neglect proceedings are automatically instituted to obtain custody of infants with positive drug screens (Roberts, 1990).

In addition, care for "boarder babies" is not discussed in this TIP. A boarder baby is an infant who is deserted by his or her parents after birth and who must remain in the hospital until the child welfare system has secured a foster care placement, which, in some instances, can take months or longer. The problem of boarder babies has increased since the late 1980s, and many boarder babies are drug-exposed.

TIP Audience and Use

It is hoped that this TIP will be read and used by a wide spectrum of people. Although it is a medically oriented document, it is written to inform and educate a range of people in the health care field (including physicians, nurses, social workers, and administrators) as well as Federal and State legislators and others who set and implement public and private policy on matters relating to maternal and child health and AOD use and abuse.

Some sections are more technical than others, and may not be appropriate for all readers. However, other sections are designed to educate and support not only people working in the field, but also parents and caretakers of infants who have been exposed to drugs.

In sum, this document is intended to be of practical use to many, and numerous suggestions are included. Please note that, despite frequent usage of the words "should" and "must," many of the suggestions offered herein are just that - suggestions - intended to assist a broad cross-section of communities in improving the care and services provided to drug-exposed infants and their families.

TIP embraces Five Key Principles

Five basic principles or key points should be kept in mind while reading this TIP.

- **Cultural and racial concerns must be considered in every aspect of the treatment process for drug-exposed infants and their families.**

The importance of developing culturally relevant services cannot be stressed enough. In many communities, services should also be multilingual. It is vital for program staff to have a keen understanding of the ways in which the culture, race, and language of the woman and her family - as well as the culture, race, and language of caretakers and service providers - affect most of the issues discussed in this TIP. Multiracial and multicultural programming is essential in today's society. People providing treatment must be aware of how their own cultural and racial backgrounds affect the delivery of services.

- **Fathers should be included in treatment to the fullest extent feasible. Treatment should be family centered.**

The involvement of the father in the treatment process should be encouraged. The role of the father is critical, often influencing the mother's preconception behavior and her activities during pregnancy, as well as after the child is born. The father plays a significant biological role in the development of the infant, and can also play a vital role in many other aspects of the child's growth. It is understood that, in some instances, it may not be possible to locate the father; however, in many instances, a father may be eager to be involved if he is

approached. Although the mother and the infant are highlighted throughout this TIP, the potential role of the father should be considered in all aspects of the treatment process as well.

In addition, programs should strive to be family-centered, working to involve the mother's and father's extended family members (grandparents, siblings, aunts, uncles) and significant others in the treatment process. Models of programs that support the family should be encouraged.

- **A lack of financial resources limits the ability of many communities to implement all the guidelines presented in this TIP. Community coordination and collaboration can help bridge the gap in resources.**

The guidelines presented herein were developed with the intention of providing assistance and support to the wide range of dedicated service providers caring for drug-exposed infants and their families within a wide range of communities and agencies. The consensus panel recognizes that many communities and agencies have insufficient resources to implement many of the guidelines offered in this TIP. However, it is hoped that people working in such communities or agencies will not be discouraged by the review of this information, and will utilize the guidelines as part of an effort to improve the availability of treatment resources. The TIP strives to encourage individuals and agencies to increase interagency coordination and community involvement - activities that can help bridge the gap in limited resources.

- **Interdisciplinary training is essential in effectively serving drug-exposed infants and their families.**

The problems in effectively serving drug-exposed infants and their families are many, challenging professionals from various disciplines to learn from each other and to work together in a coordinated manner. Training programs are essential in this coordinated learning process. Agencies should aim to creatively integrate initial and ongoing training strategies for all levels and categories of staff who serve drug-exposed infants and families.

- **The problems of drug-exposed infants are present in communities throughout the United States, cutting across all income levels.**

Despite popular mythology to the contrary, the abuse of licit and illicit drugs is widespread in middle- and upper-income communities and households across the country. Thus, drug-exposed infants are present in households representing all income levels, and are by no means an exclusive problem of low-income families.

Statement of the Problem

Epidemiology of Infant Drug Exposure

National incidence rates have been estimated of infants exposed to legal and illegal drugs *in utero*. A pilot study of 36 primarily urban hospitals estimated that 11 percent of all infants are exposed to alcohol or other drugs *in utero* each year (Chasnoff, 1989c). These figures are among the highest estimates and are probably the ones most often cited by persons advocating that increased resources be directed to this problem. The American Academy of Pediatrics (1990) estimates that one of every 10 newborns in the United States has been exposed to an illicit drug. The U.S. General Accounting Office (GAO) (1990) reviewed data from the National Hospital Discharge Survey, and found a much lower number of drug-exposed infants - fewer than 14,000. However, the GAO acknowledges that these figures represent a substantial undercount because not all women or infants are screened or tested for exposure.

Examining the same database (hospital discharges), and adjusting for underreporting, other investigators estimated that about 38,000 drug-exposed babies were born in 1987. This study also found an estimated 361 percent increase in the number of drug-exposed newborns between 1979 and 1987, with most of the increase occurring after 1983. The authors cited data suggesting that the increase in incidence slowed significantly after 1988 (Dicker and Leighton, 1991).

Local studies suggest that a large number of newborns were exposed to drugs, with the number rising sharply during the 1980s:

- New York City - From 1983 through 1987, the number of babies exposed to drugs *in utero* rose from 7.9 to 20.3 per 1,000 births. In 1989, more than 5,000 babies were born drug exposed. One Brooklyn hospital reported that 14 percent of newborns tested positive for cocaine.
- Dallas, Denver, Oakland, Philadelphia, and Houston - All these cities reported threefold to fourfold increases in the number of drug-exposed infants born between 1985 and 1988 (Kandall, 1991b).
- Boston - In 1984, a city hospital reported that 17 percent of mothers reported the use of an illicit drug at least once during pregnancy and 8 percent reported the use of cocaine. A later study (1989) in the same hospital showed that 31 percent of pregnant women had used marijuana and 18 percent had used cocaine (Khalsa and Gfroerer, 1991). (Although not yet fully documented, there is a new trend of increased heroin use throughout the country - a phenomenon not unusual given the increased use of cocaine. Historically, whenever a cocaine epidemic subsides, it is followed by an increase in heroin usage.)

More reliable national data may be forthcoming in the near future. The National Pregnancy and Health Survey, sponsored by the National Institute on Drug Abuse, will provide data on the prevalence of licit and illicit drug use by pregnant women, as well as limited data on infant birth weight and length of hospital stay. These data are eagerly awaited by researchers and practitioners in the field and will certainly be useful. However, additional epidemiologic and etiologic studies will be needed to determine the extent of the problem of infant exposure to licit and illicit drugs (Khalsa and Gfroerer, 1991).

Difficulties in obtaining national data are due in part to problems in diagnosing *in utero* drug exposure, especially to cocaine. As summarized by Bandstra and Burkett (1991), these problems include: 1) the unreliability of mothers' self-reports, 2) the limitations of urine toxicology techniques, and 3) the nature of observable clinical conditions (for example, prematurity, intrauterine growth retardation) associated with drug exposure, many of which require lengthy differential diagnoses and have multiple complex etiologies besides drug exposure. These problems are compounded when women do not self-report due to fear of prosecution.

Another reason for sketchy and inconsistent national data is the lack of uniformity in hospital policies and procedures for maternal and infant drug screening and testing. In the GAO study cited previously, medical records were examined at a small sample of hospitals. Some hospitals had no protocol for drug testing, whereas others tested only if the mother reported drug use or the infant showed signs of drug exposure. In hospitals serving primarily non-Medicaid patients, drug screening was notably less practiced, with over half of the hospitals having no protocol for identifying drug use during pregnancy. Lack of uniform hospital policies and procedures results in prejudicial and inaccurate detection practices, which may lead to stigmatization of minority children and differential approaches by social service agencies.

Dicker and Leighton (1991) point out a third possible reason for widely differing epidemiologic estimates by drawing a distinction between "drug-exposed" and "drug-affected" infants. Drug-exposed infants have been exposed to a drug or drugs (even if only once) during the mother's pregnancy. In contrast, drug-affected infants are found at birth to have symptoms diagnosed by hospital staff that are due to drug use by the mother. Thus, being drug affected is a subset of being drug exposed in epidemiologic studies, but it is not always clear which variable is being studied. *Please note that in this report, the term "drug-exposed" is used for infants and children with a history of maternal drug abuse during pregnancy and for infants who have exhibited observable effects of maternal drug abuse and who have had a positive toxicology screen at birth. The term "drug" in this report refers to legal and illegal drugs.*

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Increase in foster care placements of children under 2 years of age has also been drastic; in Massachusetts, the number of children under 2 years admitted to foster care increased 73 percent between 1988 and 1990, while in Illinois, infants under 1 year of age admitted to foster care increased by 284 percent during 1985 through 1989 (GAO, 1990). An already overburdened system must gear itself to locating foster families that will accept drug-exposed children, ensure the quality of foster homes, and provide extensive support to foster families.

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Other pressing legal issues cloud the picture. For example: What are the obligations of physicians who treat substance-using pregnant women and mothers with respect to testing for and reporting drug exposure? How

can they resolve the conflicting duties of reporting and maintaining patient confidentiality? How can lawyers shed light on the embedded issues: the concepts of fault, intent to harm, and present and future harm (Horowitz, 1991)?

Meeting the Challenge: Current Approaches

The foregoing discussion paints a grim picture of infant drug exposure. The picture is incomplete, however, without a view of the comprehensive service models that have been evolving during the last 2 decades to assist these infants and their families.

A key element of these models is a continuum of family-oriented services directed at numerous risk factors and available at a single site. Components of the model include: 1) prenatal care, labor and delivery management, neonatal care for high-risk infants, and postpartum and health and mental health care for mothers; 2) drug abuse treatment for mothers, combined with instruction and support in their parental role; 3) follow up and early intervention services for infants and toddlers; and 4) access to a wide array of support services, including income support and housing, food, employment, and legal assistance. Such models challenge the persistence and ingenuity of providers. "The multivariate systems approach . . . is a labor-intensive model. The model requires extensive knowledge of addiction; techniques for counseling, assessment, and intervention; an understanding of biological, physiological, medical, and sociological influences; and it expects an ability to mediate and to maneuver in rigid social systems and bureaucracies" (Finnegan, Hagan, and Kaltenbach, 1991).

Such models exist and flourish in many cities in the United States and are supported by various agencies of the Public Health Service, including the Center for Substance Abuse Treatment, the Center for Substance Abuse Prevention, the National Institute on Drug Abuse, and the Bureau of Maternal and Child Health of the Health Resources and Services Administration. Unfortunately, services provided by these model programs do not even begin to meet the enormous needs of drug-exposed infants and their families. Many more such comprehensive service systems need to be established throughout the United States.

Overview of Panel Recommendations and Guidelines

The recommendations and guidelines of the TIP consensus panel on Drug-Exposed Infants are derived from experiences in federally funded comprehensive models of care for drug-exposed infants and their families, and address many of the issues discussed earlier in this introduction.

- **Medical Management** - The panel provides detailed guidance on diagnosis of *in utero* drug exposure, assessment of the neonate, and effects on and treatment of infants affected by *in utero* exposure, including pharmacologic interventions for the opiate abstinence syndrome and cocaine neurotoxicity. Clinical assessment tools are recommended. Strategies for promoting positive mother- infant interaction immediately after birth are discussed, and a protocol for hospital discharge is provided.
- **Followup and Aftercare of the Infant** - A multirisk approach - one that focuses on environmental factors including drug exposure - is espoused for postpartum interventions. Early intervention services and desirable outcomes are described, and a time line chart for various interventions is specified. The panel recommends appropriate interventions for toddlers and preschoolers, along with necessary training for child-oriented professionals.
- **Psychosocial Services** - Key components of psychosocial services for families of drug-exposed infants are noted, paramount among which is drug abuse treatment for the mother. Strategies for keeping families intact are discussed. Recommendations are made regarding referral and followup for infants referred to child protective services.
- **Ethical and Legal Issues** - Fundamental ethical principles governing approaches to the treatment of drug-exposed infants and their mothers are discussed. The panel explores legal issues in assessment of mothers and infants for drug use and exposure to drugs. Guidelines in complying with reporting laws and laws governing the confidentiality of patient information are offered. Finally, elements of essential training in legal and ethical issues are noted.
- **Quality Assurance** - Guidelines are presented for some key aspects of quality assurance of service provided to AOD-using and -abusing women and drug-exposed infants.

Chapter 2 - Medical Management of The Drug-Exposed Infant

Medical management of the drug-exposed infant has emerged in recent years as a major challenge to health care professionals. This chapter presents the TIP consensus panel's recommendations and guidelines for diagnosis of *in utero* drug exposure, medical assessment of the neonate, effects of exposure to different types of drugs, guidelines for appropriate treatment, promotion of positive parent-infant interaction, and discharge criteria and instructions. As a foundation for its guidelines in these specific areas, the consensus panel recommends the following:

- **Surveillance** - Clinicians should be aware of shifting local trends due to user preferences and street market availability of particular drugs within the community. Networking with local emergency and trauma services, drug treatment providers, social service agencies, and the criminal justice system provides neonatal caregivers with an opportunity for community surveillance. However, each nursery also should monitor the changing patterns of drug exposure in its newborn population. Further, the quality of data on drug abuse patterns obtained from maternal histories or anonymous toxicology screens should be continually monitored.
- **Preconception** - Ideally, obstetricians, family practitioners, midwives, family planning clinicians, and other clinicians providing health care to women of childbearing age should provide counseling regarding abstinence from alcohol and other drugs prior to and during pregnancy.
- **Reducing Barriers to Access** - Federal, State, and local agencies should reduce barriers to the use of family planning services and increase access to early prenatal care and other health services, including drug rehabilitation.
- **Interdisciplinary Treatment** - Interdisciplinary intervention for the mother and her offspring (and the father, when possible) should be available at all points of access to care. Professionals involved in this care should include obstetricians, neonatologists, pediatricians, nurses, nutritionists, mental health professionals, social workers, substance abuse counselors, and child development specialists, at a minimum.
- **Staying Abreast of New Information** - The medical literature is replete with research and anecdotal observations on the effects of drugs and alcohol on the infant. Long-term studies of exposure to opiates are sparse, and few systematic studies of long-term alcohol effects are available (Streissguth et al., 1991; Kaltenbach and Finnegan, 1992). Recent research has documented the possible long-term effect of maternal marijuana use on the infant (Fried, 1991).¹ Longitudinal followup investigations on the effects of *in utero* cocaine exposure are in progress. Clinicians are encouraged to review the available literature, much of which is cited in the bibliography included in this TIP.

Attempts to assess the effects of drug exposure on newborns are confounded by numerous medical and environmental variables. However, acknowledging these limitations, the TIP consensus panel offers these guidelines to the medical management of drug-exposed infants. *In utero* exposure to opiates (heroin and methadone) and cocaine is emphasized. Many of the suggested approaches are also applicable to infants exposed prenatally to other drugs, including alcohol. It is very important to remember that alcohol use frequently coexists with other forms of substance abuse. A brief discussion of alcohol-related effects on infants is included for information.

Readers should note that an earlier publication in this series, *Pregnant, Substance-Using Women*, provides extensive information on labor and delivery management and infection control for high-risk pregnancies. This panel endorses those recommendations.

Alcohol Use in Pregnancy²

Abuse of alcohol is a significant societal problem in the United States; approximately 18 million Americans are chronic consumers of alcohol. Current estimates indicate that between 8 and 11 percent of women of childbearing age are either problem drinkers or alcoholics. Alcohol abuse exists within all socioeconomic levels of society. Review of drinking habits during pregnancy should form an essential part of perinatal history taking.

No safe level of alcohol consumption during pregnancy has been determined. Alcohol exposure *in utero* may result in a spectrum of abnormalities of fetal growth and development. Maternal consumption of 2 to 3 ounces of alcohol daily, often in association with "binge drinking," is frequently associated with fetal alcohol syndrome (FAS). Lesser intake of alcohol may produce subcombinations of signs of FAS; these lesser signs have been called fetal alcohol effects (FAE).

The effects of alcohol abuse during pregnancy can be summarized as follows:

1. **Adverse Pregnancy Outcome**, including an increased risk of spontaneous abortion.
2. **FAS** - The worldwide incidence of FAS is 1-3 births per 1,000 live births. To make the diagnosis of FAS, one abnormality from each of the following categories must be present:
 - a. Prenatal or postnatal growth retardation; failure to thrive (weight, length, and / or head circumference less than the 10th percentile).
 - b. Central nervous system dysfunction, including intellectual, neurologic, and behavioral deficits manifested as mild to moderate mental retardation, hypotonia (poor muscle tone), irritability in infancy, and later hyperactivity in childhood. Mental abnormality occurs in 85 percent of FAS children, and although IQ scores vary, affected children rarely show normal mental ability.
 - c. Facial dysmorphism (structural abnormalities) including at least two of three characteristics:
 1. Microcephaly (head circumference less than the 10th percentile).
 2. Microphthalmia (abnormal smallness of the eye) or short palpebral fissures, ptosis (drooping eyelid), strabismus (imbalance of the eye muscles), or epicanthal folds (folds of the skin of the upper eyelid over the eye).
 3. Poorly developed philtrum, thin upper lip (vermillion border), short upturned nose, or flattening or absence of the maxilla (upper jaw).
3. **FAE** - Lesser degree of effect.

Diagnosis of *In Utero* Drug Exposure

Maternal Substance Use History

A maternal AOD use interview should be conducted at the earliest point of access into the health care system. (If possible, information about paternal substance use should also be obtained by interviewing the father or questioning the mother.) Despite concerted efforts by health care professionals to promote prenatal care, the mother may not have received such care and the delivery hospitalization may be the only opportunity to elicit information on the nature and extent of the infant's *in utero* exposure to drugs and alcohol. The mother's concern for her infant's health may encourage valid responses; conversely, fear of legal reprisals or loss of custody of the infant may cause the mother to deny drug use.

The AOD use interview should be conducted in as private a setting as possible and in a nonthreatening and nonjudgmental manner. Guidelines for the maternal substance use assessment, including psychosocial and mental health assessment, were developed by the consensus panel on *Pregnant, Substance-Using Women* and are repeated here with minor modifications.

1. The AOD use history taking should include legal and illegal drugs (prescription drugs, alcohol, and cigarettes), and should cover:
 - Duration of use, including age of first use
 - Frequency, type, and amount of drugs used and periods of abstinence
 - Route of administration
 - Social context of use (with whom the patient uses, where and when she uses)
 - AOD abuse treatment history
 - Support group involvement
 - Consequences of use (self-perceived and objective)
 - Relapse factors
 - Family history of use
 - Motivation for treatment
 - Motivation for continued use of drugs

- Urine toxicologies as needed: A urine toxicology is indicated when an adequate drug history cannot be obtained from the mother and she is manifesting symptoms of possible addiction or withdrawal and when the child is showing signs or symptoms of withdrawal.
2. A psychosocial assessment should include:
 - Support systems (role of the patient in her family support system and the stress created by that system)
 - Patient's attitude toward the birth of this child and her perception of her ability to parent this child and any older children
 - Role of the father, both in the mother's life and his potential role with the child
 - Education and employment
 - History of physical, sexual, and emotional abuse, both as a child and as an adult
 - Current life situation, including housing, transportation, child care, monetary support, and legal considerations or problems.
 3. The mental health assessment should cover:
 - Mental status examination
 - Psychiatric symptomatology
 - Psychiatric history and treatment
 - Suicide risk
 - Family psychiatric history
 - DSM-III-R diagnosis
 - Treatment recommendations.

Standardized psychiatric evaluation tools can be helpful in diagnosis and followup. Further, liaison and ongoing contact must be maintained with other members of the assessment and treatment team.

Treatment Planning

Treatment planning for mothers and involvement of representatives from all participating agencies should include referral to an appropriate AOD abuse treatment program and continued involvement with medical and psychosocial agencies. Adequate arrangements should be made to ensure that the mother can get to the treatment facility, which may, in certain instances, require the provision of transportation for the mother to the location. An in-depth treatment plan should be developed for the infant through multidisciplinary efforts of doctors, nurses, social workers, and others. The mother and father should be given the opportunity and urged to take part in treatment planning. If assessment reveals that the infant may be at risk for future harm due to the mother's potential for abuse or neglect, a report should be made to the child protective services agency so that further evaluation can occur. [Chapter 4](#) sets forth guidelines for referrals to child protective services. At a minimum, the treatment team must develop a clear followup plan for the infant upon discharge from the hospital, and must arrange for careful monitoring of compliance with the plan. Guidelines for followup are detailed in [Chapter 3](#).

Medical Assessment of the Drug-Exposed Neonate

Physical Examination

A thorough physical examination of the neonate should include accurate assessment of weight, length, and head circumference and a standardized assessment of gestational age. Special attention should be paid to signs of intrauterine growth retardation, microcephaly or decreased head circumference, prematurity, congenital infection, and major and minor congenital malformations. Various tools and scoring systems can be used to chart and compare the infant's neuromuscular and physical maturity and size to normal ranges for infants ([Ballard et al., 1977](#); [Ballard et al., 1979](#); [Brazelton, 1984](#); [Lubchenco et al., 1966](#)). The Newborn Maturity Rating and Classification chart is reproduced in [Exhibit 1](#).

Screening for Congenital Infection

Drug-exposed infants are at increased risk of acquiring infections transmitted from mothers whose lifestyles include unsafe sexual practices or intravenous drug abuse. Assessment of the mother for sexually transmitted diseases and human immunodeficiency virus (HIV) should be incorporated into the prenatal care setting and delivery hospitalization.

1. Quality improvement guidelines should be established within each institution to assess periodically the prevalence of HIV infection among pregnant women anonymously screened on a random or consecutive sample population.
2. AOD-using pregnant women should receive routine screening for syphilis, hepatitis B, gonorrhea, and chlamydia.
3. AOD-using pregnant women should be offered confidential or anonymous screening for the HIV-1 virus with appropriate pre- and post-test counseling.
4. Quality improvement guidelines should be established within each institution to review the incidence of sexually transmitted diseases among pregnant women and their impact upon the infants and the health care delivery system.
5. Quality improvement guidelines should be established within each institution to ensure utilization of updated recommendations for medical management of neonates exposed to HIV, hepatitis B, syphilis, gonorrhea, and chlamydia (Prober and Gershon, 1991).
6. Quality improvement guidelines should include universal precautions for infection control in the delivery service and neonatal nurseries.

In Utero Exposure To Opiates: Effects And Treatment

Effects of *In Utero* Heroin Exposure

The effects of heroin on the neonate are as follows:

1. **Low Birth Weight** - The low birth weight is due primarily to symmetric intrauterine growth retardation. Low birth weight may also be due to prematurity. In either case, low birth weight results in the slowing of both body and head growth. (See definitions of medical terms in [Appendix F](#).)
2. **Meconium Aspiration** - Meconium aspiration may be caused by hypoxia in association with antepartum or intrapartum passage of meconium secondary to fetal stress.
3. **Neonatal Abstinence Syndrome (Withdrawal)** - Neonatal abstinence syndrome occurs in about 60 to 80 percent of heroin-exposed infants. Its onset is usually within 72 hours of birth, with possible mortality if the syndrome is severe and untreated. The syndrome involves several body systems. Central nervous system (CNS) signs of abstinence include irritability, hypertonia, hyperreflexia, abnormal suck, and poor feeding. Skin abrasions may result from general hyperactivity. Seizures are seen in 1 to 3 percent of heroin-exposed infants. Gastrointestinal signs include diarrhea and vomiting. Respiratory signs include tachypnea, hyperpnea, and respiratory alkalosis. Autonomic signs include sneezing, yawning, lacrimation, sweating, and hyperpyrexia. If the infant is hypermetabolic, the postnatal weight loss may be excessive and subsequent weight gain suboptimal unless higher caloric intake is provided. In cases demonstrating signs suggestive of the abstinence syndrome, other diagnoses should also receive the clinician's full attention. For example, sepsis, metabolic disorders, and CNS hemorrhage or ischemia should be considered in making the differential diagnosis. Premature infants seem to manifest fewer overt symptoms of opiate abstinence syndrome. These differences may be due to the developmental immaturity of the preterm CNS, which might ameliorate the clinical appearance of abstinence symptoms, or to variations in total drug exposure due to a shortened gestation (Doberczak, Kandall, and Willets, 1991).
4. **Delayed Effects** - Delayed effects include subacute withdrawal with symptoms such as restlessness, agitation, irritability, and poor socialization that may persist for 4 to 6 months.

5. **Sudden Infant Death Syndrome (SIDS)** - Epidemiologic studies suggest an association between SIDS and interuterine exposure to opiates (including methadone), but somewhat weaker links between SIDS and cocaine exposure ([Kandall and Gaines, 1991](#)).
6. **Effects of mother's behavior** - Adverse effects may be due to the life circumstances and behavior of the mother who uses heroin. Lack of prenatal care, poor nutrition, medical problems and the abuse of other drugs pose significant risk to the mother and the fetus. In addition, heroin use can cause sexual disinhibition, which increases the possibility of the mother's engaging in behaviors that place her at high risk for contracting HIV, such as sharing needles. Or the addicted mother may engage in sex for drugs with partners infected with HIV and other sexually transmitted diseases (STDs).

Effects of In Utero Methadone Exposure

Maternal methadone maintenance is a valuable treatment modality when administered under medical supervision. Although methadone poses some threat to the fetus, it is important to contrast the benefits of methadone in pregnancy with the risks associated with the continuing use of heroin. For this reason, methadone maintenance is often recommended for pregnant opioid-dependent women.

Benefits of Methadone Maintenance During Pregnancy

1. **Assists women in staying heroin free** - The purpose of methadone is to provide an opioid-dependent individual with a legal alternative to an illicit substance, the effects of which can be monitored by a medical professional as the individual goes through withdrawal and after withdrawal. Methadone maintenance reinforces the woman's desire to abstain from using heroin. Off heroin, the woman is in a better position to manage her life so as to maximize the possibilities for a healthy lifestyle for herself and her baby.
2. **Leads to more consistent prenatal care** - Studies have shown that methadone maintenance leads to more consistent prenatal care, giving medical providers and others involved the opportunity to better manage the pregnancy and the various aspects of the pregnant woman's care.
3. **Lessens possibility of fetal death** - Maternal opiate withdrawal can cause fetal death ([Hoegerman and Schnoll, 1991](#)). Significant opiate use is associated with increased pregnancy loss. The incidence of pregnancy loss is definitely decreased if the woman is maintained on methadone.
4. **Lessens decreased fetal growth and improves growth of newborn** - Significant opiate use is associated with decreased fetal growth and affects the growth of the newborn. Once the baby is born, the baby will often develop more normally if the mother has been maintained on methadone.
5. **Reduces risk of HIV infection** - Methadone maintenance reduces the transmission of HIV (Blix et al., 1988; [Cooper, 1989](#)). Women maintained on methadone do not spread the growth of the HIV virus as do women who use morphine, cocaine, and heroin ([ADAMHA News \[2\], 1992](#)). The reason for the reduced HIV rate is that the use of methadone decreases the practice of high-risk behaviors (unsafe sex and the sharing of used intravenous needles that may contain HIV-infected blood products).
6. **Enables the woman to breastfeed her infant** - Breastfeeding is not contraindicated if the woman is methadone maintained. Thus, if they are HIV-negative and free of other drug use, women on methadone can be encouraged to breastfeed their babies. Given the well-established importance of breastfeeding in the mother-infant bonding process, the fact that methadone-maintained women can often breastfeed their infants is of vital significance. This advantage to methadone should be emphasized by providers when assisting women in the decisionmaking process regarding whether to begin methadone maintenance.

Risks of In Utero Methadone Exposure

Despite the significant advantages of methadone to an opioid-dependent pregnant woman, dangers to the fetus and to the newborn still exist, as described below.

1. **Low Birth Weight** - *In utero* exposure to methadone may lead to low birth weight caused by symmetric fetal growth retardation involving fetal weight, length, and head circumference. There is a lack of consensus on the appropriate methadone dosage schedule during pregnancy. Some studies

indicate that a higher dose in the first trimester leads to a more optimal birth weight. Thus, a higher dosing schedule during this period may be considered (Kandall et al., 1976).

2. **Neonatal Methadone Abstinence Syndrome** - Although the neonatal methadone abstinence syndrome is similar to that of heroin, it is typically more severe. Whether severity is related to maternal dosage is controversial (Harper et al., 1977). Late withdrawal can occur at 2 to 3 weeks of age, and subacute withdrawal can persist until 6 months of age. These phenomena may be related to variations in the metabolism of methadone due to placental transfer or neonatal metabolism. Methadone is also known to accumulate in CNS tissue (Finnegan and Kaltenbach, 1992.)
3. **Seizures** - Seizures attributed to withdrawal will be seen in some drug-exposed infants. For example, in one study of 301 neonates passively addicted to narcotics, 18 had seizures attributed to withdrawal (Herzlinger et al., 1977). Some studies have shown that infants exposed to methadone may have an increased incidence of seizures (Herzlinger et al., 1977; Harper et al., 1974). Others in the field believe that it is actually the use of diazepam and phenobarbital that increases the incidence of seizures in methadone-exposed babies. The latter recommend the use of paregoric.
4. **Thrombocytosis** - At 4 to 10 weeks, methadone-exposed neonates are at risk to develop thrombocytosis, which may persist for 6 to 10 months (Burstein et al., 1979).
5. **Hyperthyroid State** - Elevation of T3 and T4 during the first week of life has been documented (Jhaveri et al., 1980).
6. **SIDS** - When controlled for other high-risk variables, the rate of SIDS among opiate-exposed infants is about 3-4 times higher than in the general population. The increased rate of SIDS is less impressive for cocaine-exposed infants (Kandall and Gaines, 1991; Kandall et al., 1993).

In Utero Exposure To Cocaine: Effects And Treatment

Effects of Cocaine Exposure on the Neonate

The abuse of cocaine became an alarming problem during the last decade. It is estimated that up to 8 million Americans use cocaine regularly and 30 to 40 percent of cocaine addicts are women. Cocaine use by pregnant women has multiple adverse influences on the mother's health, pregnancy outcome, and the well-being of the infants as discussed in recent review articles (Bandstra and Burkett, 1991; Dixon and Bejar, 1989; Dixon, Bresnahan, and Zuckerman, 1990; and Kandall, 1991, a and b). These effects are summarized in Exhibit 5, and are discussed in detail below.

As with heroin addiction, adverse effects may be due to the life circumstances and behavior of the mother as well as to the pharmacologic properties of cocaine itself.

Lack of prenatal care, poor nutrition, medical problems, and abuse of other drugs and alcohol pose significant risk to the mother and the fetus. In addition, cocaine use increases the possibility of the mother's engaging in behaviors such as unprotected sex that place her at risk for contracting HIV.

The pharmacologic action of cocaine inhibits uptake of norepinephrine in the synaptic cleft, thus leading to vasoconstriction, hypertension, and tachycardia. In animal models, cocaine increases uterine vascular resistance and decreases uterine blood flow with resulting fetal hypoxemia.

Therefore, cocaine may play an etiologic role in causation of *abruptio placentae*, premature labor, intrauterine growth retardation, and fetal vascular disruption. Cocaine exposure causes a direct neurotoxicity manifested by neurobehavioral disturbances that are usually less striking than those associated with opiate abstinence syndrome.

These neurobehavioral disturbances may be transient, and usually do not require treatment. An encephalopathic syndrome - including irritability, tremulousness, lethargy, somnolence, labile state, decreased habituation, and visual tracking difficulties - has been described in cocaine-exposed newborn infants by many investigators. In addition to clinical signs of cocaine-induced neurotoxicity, transient encephalographic abnormalities can be demonstrated in this population of infants. Besides clinical and encephalographic

abnormalities, echoencephalographic abnormalities are found in some cocaine-exposed infants (Dixon and Bejar, 1989). Lesions varying from ischemic injury with cavitation to intraventricular hemorrhage and ventricular dilation are observed in 8-14 percent of the study population. Cerebral infarctions have also been described in other reports. In some infants, physiologic dysfunction is indicated by alterations in vital signs including tachycardia and hypertension, and cardiac arrhythmias. The risk of sudden infant death syndrome in this population of infants may be increased, but large epidemiologic studies are needed in order to differentiate between effects of cocaine and other factors, such as low socioeconomic status, polydrug abuse, and smoking.

Long-term effects of intrauterine cocaine exposure, as well as poly-drug exposure, are described in anecdotal reports, and include attention deficits, flat apathetic moods, decreased fantasy play, and other observations. However, long-term followup studies of cocaine-exposed children are scarce at present (Chasnoff et al., 1992).

Subtle neurobehavioral aberrations may persist beyond the neonatal period. Cocaine may produce long-term neurodysfunction, which is now being described anecdotally among the first cohort of babies exposed to crack *in utero* as they enter nursery school. The biologic vulnerability of infants exposed to crack *in utero* is modulated by the environment. The poor psychosocial, nutritional, medical, and socioeconomic status of the mother can all contribute to long-term neurodysfunctional sequelae in the infant (Mayes et al., 1992; Zuckerman and Frank, 1992). Additional risk factors - including intrauterine growth retardation, CNS pathology, prolonged hospitalization, and lack of intellectual nurturing - must be taken into consideration in evaluation of long-term neurobehavioral outcome of cocaine-exposed infants.

Treatment for Cocaine-Exposed Neonates

Treatment for the neonate demands an appropriate nursery environment, comprehensive assessments, pharmacologic intervention, and clinical diagnostic studies.

1. **Optimal Nursery Environment** - Such an environment features sound primary nursing care, gentle handling by as few caretakers as possible, and an avoidance of stimuli such as light and noise that will irritate the baby. To facilitate and promote optimal infant growth and development, nursery personnel should carefully monitor feeds, initiate strategies to facilitate intake for those infants experiencing feeding difficulties, observe for feeding intolerance or necrotizing enterocolitis, provide opportunities to interact with parents and environment as the infant is able to tolerate them, and provide primary nursing to facilitate parent-infant interactions.
2. **Brazelton Neonatal Behavioral Assessment Scale** - Use of the Brazelton Neonatal Behavioral Assessment Scale (Brazelton, 1984) is encouraged. This scale has been used extensively to evaluate newborn behavior such as habituation and responsivity to stimuli (faces, voices, light, bell, rattle, etc.); state (sleeping, alertness); characteristics of changes in state (irritability, inconsolability); and neurological and motor development. Although clinical expertise is demanded to administer the Brazelton Scale, programs will find it useful in evaluating infants exposed to drugs (Finnegan, 1986).
3. **Neonatal Neurotoxicity Assessment** - While asymptomatic infants do not need to be systematically assessed for neonatal neurotoxicity, consideration should be given to developing scoring criteria for those infants who are symptomatic. In the presence of significant withdrawal symptoms, other etiologies, including polydrug and alcohol exposure and metabolic problems, should be explored.
4. **Pharmacotherapy** - If irritability persists in an infant, a short course of phenobarbital is recommended.
5. **Central Nervous System Imaging** - Cranial sonograms are not routinely recommended, but recent literature is suggestive of CNS abnormalities, including hemorrhagic ischemic lesions in some drug-exposed infants. (Dixon and Bejar, 1989; Heier et al., 1991 a and b). As yet, evidence is insufficient to support a mandate for cranial sonograms in all cocaine-exposed infants. However, special consideration should be given to specific neuroimaging of cocaine-exposed preterm infants, infants whose head circumference falls below the 10th percentile on standardized fetal growth curves, and infants with abnormal neurologic signs, neurobehavioral dysfunction, or seizure activity.
6. **Assessment for Congenital Malformations / Vascular Disruptions** - Clinicians should have a heightened awareness of the possibility of uncommon but significant congenital malformations or vascular disruptions reported in cocaine-exposed neonates. Systems that may be affected include the genitourinary tract, cardiovascular system (congenital heart malformations), gastrointestinal tract, and skeletal system. Echocardiography and abdominal ultrasound are not currently recommended as

routine assessments in cocaine-exposed infants, but should be performed based on clinical indications.

7. **Sudden Infant Death Syndrome** - As indicated earlier, SIDS is a multifactorial problem, and opiate exposure is known to increase the neonate's risk of SIDS. There is some controversy over the incidence of SIDS in cocaine-exposed infants, but crack cocaine does appear to raise the risk slightly over controls. Data also suggest that cocaine-exposed infants may exhibit respiratory dysfunction. There are no indications that apnea monitoring decreases the incidence of SIDS. Routine home apnea monitoring for drug-exposed infants is therefore not recommended.

Promoting Positive Mother-Infant Interaction

Hospitals can promote positive interaction between parents and infants by adopting liberal visiting policies and mother-infant interaction time for newborn nurseries. Two other areas of concern are breastfeeding and instruction of mothers in handling drug-exposed infants.

Breastfeeding Drug-Exposed Infants

Breastfeeding is a key area of concern, especially among substance-using women. The advantages of breastfeeding are many, and are well documented. Benefits include the fact that breastfeeding strengthens the bond between the mother and the infant - an advantage that is of vital importance. Despite the instances described below, when breastfeeding is contraindicated, the decision on the part of service providers to advise women against breastfeeding should not be made without careful thought and training, taking into account the particular circumstances of the individual woman. Service providers must often become active breastfeeding advocates, encouraging the mother to breastfeed despite initial resistance to do so and educating her on breastfeeding's advantages to both herself and the newborn.

Nonetheless, there are instances when breastfeeding of drug-exposed infants is contraindicated. Since most drugs are secreted in breast milk, it has often been the practice to advise drug-using mothers not to breastfeed. Women who have been actively using drugs through the pregnancy and after the delivery have been discouraged from breastfeeding because of a number of factors including possible drug toxicity from diverse agents in varying levels, including the risk of exposure to drugs used intravenously, and the mother's medical and nutritional problems associated with continued drug use. Cocaine readily passes into breast milk and may lead to neonatal neurotoxicity, including irritability, tremors, brisk reflexes, mood lability, and even seizures. In addition, breastfeeding is contraindicated if the mother is HIV positive. (It should be noted, however, that the HIV status of the mother may not be known to the care provider or the mother.)

Discharging the Drug-Exposed Infant from the Hospital

It is often quite difficult to follow an AOD-using mother and her newborn after release from the hospital, and thus it is vital that the infant and the mother not be discharged too early. According to the Newborn Assessment Score, most babies (96 percent) are symptom-free of withdrawal seizures by the third or fourth day after birth and might otherwise be ready to be discharged from the hospital. However, a small but significant percentage of babies present with withdrawal seizures within 7 to 10 days after birth. For this reason, it is important to closely monitor the drug-exposed infant to determine if he or she needs to remain in the hospital after 4 days. Other medical, social, or environmental issues may further prolong the need for hospitalization ([Doberczak et al., 1988](#)).

Discharge Criteria

The infant's discharge should occur after the following criteria are met:

1. The infant is taking oral feeds and gaining weight satisfactorily.
2. The infant is physiologically stable (has normal vital signs including blood pressure).
3. The infant is showing neurobehavioral recovery (can reach full alert state, responds to social stimuli, and can be consoled with appropriate measures).
4. All necessary assessments have been completed, since adherence to followup schedules cannot be ensured.

Discharge Instructions

1. The parent(s) or alternate primary care provider should receive anticipatory guidance (oral and written) regarding late and subacute withdrawal, seizures, behavioral interventions, and medications (side effects, route of administration, dose, etc.).
2. A home evaluation should be performed on all drug-exposed infants or those with multiple risks by a public health nurse or a protective social service worker within 7 days of discharge, when feasible.
3. A follow-up appointment for pediatric care should be scheduled within 2 to 4 weeks.
4. Mothers and fathers who are not already enrolled in drug abuse treatment and need to be should be referred to an accessible and suitable treatment program prior to the infant's discharge.
5. Facilitation of mother's postpartum gynecologic care and family planning should be incorporated into discharge planning of the infant.
6. To promote quality improvement, discharge planning instructions should be documented in medical records, and a discharge summary of the hospital course should be given to parents or alternate primary caregiver.

The following chapter gives further guidance on proper monitoring and care of the drug-exposed infant following discharge from the hospital.

Drug abuse during pregnancy is associated with medical, psychological, and economic problems that require extensive evaluation by qualified service providers. Mothers and fathers of drug-exposed infants need substance abuse treatment and a wide array of services to support them in their parenting role. Provision must be made for such services prior to an infant's discharge. [Chapter 4](#) contains recommendations regarding psychosocial services for families of drug-exposed infants.

Endnotes

¹ The research documents aspects of neurobehavioral development in 36- and 48-month-old children. At 48 months, significantly lower scores in verbal and memory domains were associated with maternal marijuana use after adjusting for confounding variables. This negative relationship is the first reported association beyond the neonatal stage, and may represent a long-term effect of the drug upon complex behavior that, at a younger age, had not developed and/or could not be assessed.² Information in this section is based on data from Pietrantonio and Knappel, 1991.

Chapter 3 - Followup and Aftercare of Drug-Exposed Infants

Drug-exposed infants should not be viewed as a homogeneous group but as individual at-risk infants presenting with a broad spectrum of possible effects, ranging from healthy term newborns with no apparent effects to high-risk births with significant effects. Living in a drug-abusing family is, in itself, a significant risk factor, regardless of prenatal exposure. Maternal drug use (and paternal drug use as well) represents a health, biological, and psychosocial risk to the developing fetus and a social risk to the young child. The primary focus of the addicted woman is characteristically on her drug of choice, not on her child. A child whose mother

abuses drugs often lives in a chaotic environment. Prenatal drug exposure and suboptimal home environments are highly correlated. In combination, they have a synergistic and devastating effect on the child's health and development (Kaltenbach and Finnegan, 1984, 1987, 1988).

Because the infant exists as part of a mother-child dyad, effective treatment must occur within the context of that relationship, as the mother often serves as the gatekeeper for the child's access to services. Knowledge of other siblings, extended family, the father, friends, neighbors, and other caregivers is also crucial to treatment. Followup and aftercare services should also be based on a multicultural and multilinguistic model that takes into account the cultural backgrounds of the mother, the father, and the extended family, as well as the service providers. Staff should reflect the different cultural and racial backgrounds of the communities being served. When appropriate, bilingual staff should be hired or other provisions made so that the inability to speak English is not a barrier to care. In sum, to be effective, treatment must occur within the cultural context of the mother and father, the extended family, and the community.

Knowledge of specific drug exposure is necessary for the appropriate medical management and treatment during the newborn period; the type of pharmacotherapy used in treating neonatal abstinence varies according to the specific drugs or combinations of drugs used by the mother. But followup and aftercare should not be based on a deficit model that assumes and screens for specific abnormalities caused by specific drugs. Rather, followup and aftercare should be based on a multirisk model that takes into account not only the prenatal drug exposure but also the medical status of the mother and the caregiving environment of the infant.

All health care and other service providers should consider the possibility that a number of environmental factors may contribute to specific deficits that have been attributed to drug exposure, as outlined below.

Experience with drug-using mothers and their children has demonstrated that drug exposure is only one of a number of risk factors that may affect the lives of the mothers and children. Other risk factors include:

- Chronic poverty
- Poor nutrition
- Inadequate or no prenatal health care
- Sexually transmitted diseases, including HIV exposure
- Domestic violence
- Child abuse or neglect
- AOD abuse within the family (including the father and the extended family)
- Homelessness, transient or inadequate living arrangements, or substandard housing
- Unemployment
- History of incarceration
- Low educational achievement
- Poor parenting skills
- Discrimination based on race, gender, or culture.

The lack of sufficient training among providers also affects the quality of the followup care given to drug-exposed infants and families.

To counter the drug-exposed child's early disadvantages, service providers must be prepared to intervene early, often, and from many perspectives. Above all, health care and other service providers should not adopt the attitude that all drug-exposed infants are doomed to an unhappy, unhealthy life. Many, if not most, can eventually lead productive lives, given adequate intervention, education, and treatment services.

The following recommendations address interventions for infants and toddlers, the transition to the preschool period, and training for child-oriented professionals. In general, many services require pediatric supervision by a specially trained physician.

Early Interventions For Infants

1. **Components** - Because of their distinctive needs, drug-exposed infants should receive more than the standard medical followup. Such followup should preferably be carried out under the supervision of a specially trained pediatrician. Followup interventions include but are not limited to:
 - Nutrition (especially if inadequate sucking reflex is evident)
 - Psychomotor assessment and monitoring of development
 - Vision and hearing screening
 - Speech and language assessments and therapy
 - emotional development assessments and therapy
 - Play therapy
 - Early educational needs assessments
 - Physical therapy
 - Immunization (see Exhibits 6 and 7).
2. **Referrals** - All health care and other service providers, including physicians, should stay abreast of available community services for drug-exposed infants and their families. Administrators should develop clear procedures to ensure that referrals are made to the appropriate resources. (For example, procedures might clarify whose responsibility it is to make referrals, such as case managers or social workers.)

Examples of routine health care referrals for drug-exposed infants and their families should include referrals to Federal programs such as:

- Early Periodic Screening, Diagnosis and Testing Program
- Maternal and child health services
- Community health centers
- Healthy Start Program.

Interventions for Toddlers

1. **Early childhood programs** - For toddlers who have been receiving early intervention services and whose behavior and development are within normal limits, interventions would include quality, developmentally based early childhood programs like Head Start (modified for younger children with appropriate staffing and curriculum), preschool programs, and parent-child groups. Quality early childhood programs offer children and their parents the opportunity to be exposed to other adults who have different approaches to childrearing, to try out new activities and learning experiences within a supportive environment, to participate as part of a group, to interact with peers, to receive feedback from others about their behavior, and to experience success and a sense of accomplishment. Children at risk for school failure because of their drug exposure or drug-using home environment can master these critical tasks within an integrated early childhood program.
2. **Individual Therapy** - Some children may not have received early intervention, or may still need individual therapy. Interventions, including speech and language services and physical and play therapy should be based on individual profiles of abilities and weaknesses. Low child: teacher ratios (1:1 being optimal) are recommended to allow for quality programming and an individualized focus.
3. **Self-Regulation** - Early childhood marks the beginning of self-regulation. Specific strategies to support self-regulation include (Appendix A, Section V):
 - An orderly, consistent, child-appropriate environment.
 - Predictable routines and consistent schedules.
 - Clear expectations and rules.
 - Clear patterns for transitions (such as a daily routine, warning signals, and signals to move to next activity).
 - Offering choices to children.
 - Praising a child's efforts, not just successes, each day.
 - Using anticipatory guidance to avoid difficult situations.

- Explaining how a child's actions affect others.
- 4. **Relationships** - Strategies to support secure relationships with ongoing caregivers include:
 - Individual attention, encouragement of mutual respect, and celebration of each person to build healthy self-esteem.
 - Activities that foster self-esteem in both mother and child.
 - Labeling of feelings, so the child can learn to identify and express a range of emotions.
 - Clear boundaries within adult-child relationships.

Transition to the Preschool Period

Transition from the toddler to preschool period should involve careful planning and preparation with the mother and child to ensure compliance with the new program. Early intervention and developmentally based parent-child and early childhood programs should continue to provide services within a family-centered model, and should feature low child to teacher ratios of 4:1 for multirisk children. In addition, class size should remain small, with no more than eight children and two teachers per classroom. Lower ratios and small class size ensure that the children receive the individualized attention critical to their educational development.

To deal adequately with the complex problems of multirisk children in a school setting:

1. Needed therapeutic services should be provided:
 - Speech and language services
 - Physical therapy
 - Occupational therapy
 - Play therapy.
2. Teachers should be provided with training to:
 - Understand addiction issues in general.
 - Understand women's addiction issues and family systems.
 - Understand cultural and racial factors in the family's background.
 - Recognize behavioral cues in individual children to promote the child's self-regulation.
 - Provide a consistent, predictable, well-structured environment to promote the child's self-regulation.
 - Plan for transitions to promote the child's self-regulation.
 - Address issues relating to addiction, abuse, and violence.

Quality Assurance Checklist

To ensure the quality of followup and aftercare services to the drug-exposed child, the hospital AOD abuse treatment program should provide the following services:

- Qualified staff and inservice education programs.
- Interdisciplinary staff that includes AOD treatment providers.
- Appropriate AOD treatment services for the mother as well as the father.
- Significant involvement of mother and child dyad; if the father is present, he should be involved.
- Child to staff ratio not exceeding 3:1 up to 3 years of age in the early intervention program.
- Transportation.
- Regular medical exams according to schedule.
- Up-to-date immunizations.
- Weekly monitoring visits during first 3 months, and monthly visits up to 18 months; visits should be conducted by the organization responsible for case management.
- Availability of visiting nurses.
- Regular reports to and from social services.
- Ongoing relationship with child protective services.

- Long-term retention of mothers in the program.
- Mechanism for peer review.

Refer to [Appendix B](#) for sample comprehensive programs for substance-using women and their infants.

Training for Child-Oriented Professionals

Health professionals often lack training and experience working with substance-abusing women, addicted families, prenatal drug exposure, and effective intervention strategies. Educators and health care providers must understand addiction, family functioning, and be able to communicate effectively with families.

Child-oriented professionals need specific training and supervision in: taking AOD histories; addiction models and issues for women; family systems - especially regarding the addicted family; prenatal drug exposure (medical, developmental, and behavioral outcomes); child development; family-focused interventions; parent-child interactions; intervention strategies for mothers and children (and fathers); HIV and its relationship to AOD abuse; treatment and referral strategies; and the impact of culture and ethnicity on service delivery.

All professionals working with addicted people and their children must have access to regular clinical supervision. Clinical supervision provides information, support, and stress management.

Endnotes

¹ IDEA was formerly known as P.L. 99-457. The Education of the Handicapped Act Amendments of 1986. In 1990, the title of the Act was changed, and some changes were made as well in the content of the law. (For instance, greater emphasis is now placed on the transition component from toddlers to children aged 3 to 5.) The numbers of the law were also dropped when referring to the Act, since the numbers change each time the law is reauthorized. In 1992, the Act is authorized under P.L. 101-476.

Chapter 4 - Psychosocial Services for Drug-Exposed Infants and Their Families

A broad range of psychosocial services is required for an extended period of time to address the needs of the infant for a nurturing and safe environment and the mother's multiple needs as a recovering addict, parent, and perhaps, head of household.

This chapter addresses key components of psychosocial services and the assistance needed to obtain them. Strategies for keeping families intact are explored and emphasized. Despite these strategies, drug-exposed infants often must be separated, even if temporarily, from their parents. Accordingly, the panel makes specific recommendations regarding referral to child protective services, followup for infants in child protective services and foster care, and assuring the quality of services provided to them.

Public child welfare agencies (in each State, county, or city) are mandated to perform a broad array of services for infants who have been abused, abandoned, or neglected, including foster care placement and managing family unification after separation. It is often the child welfare worker who coordinates this unification.

Comprehensive Psychosocial Services

In the absence of a stable, nurturing home environment, the infant already compromised by drug exposure probably will be at increased risk of adverse outcome throughout infancy and childhood. A comprehensive range of social services can promote stability and nurturing.

Several factors should be kept in mind when developing comprehensive social services for drug-exposed infants and their families.

- Efforts should be made to guarantee that services are sensitive to the cultural and racial backgrounds of the women using the services.

Innovative means of accomplishing this cultural competency, including extensive community involvement, should be explored.

Community involvement might include participation from: concerned families and residents in the community, community organizations, and church groups, and current or former patients in the program and their families. Community involvement can go a long way toward addressing not only issues of cultural sensitivity, but also concerns about lack of resources and funding through the contribution of volunteer services.

- Utilization of outreach workers can provide programs with an important way to augment a wide range of services, encouraging more "one-on-one" contact with the mother and her family. Program administrators should work to ensure that sufficient funding is available to hire and maintain outreach workers as key personnel in program operations.
- Community-based organizations (CBOs) should be utilized to support the range of social services that can be offered to the substance-using woman and her family.

Programs operating out of large institutions (such as hospitals) should strive to develop collaborative relationships with CBOs. Efforts should be made to establish ongoing mechanisms for networking between institutionally based programs and CBOs serving drug-exposed infants.

- Whether provided at a single site or at a number of agencies throughout the community, services available to women and families caring for drug-exposed infants should be accessible, coordinated, and comprehensive. Linkages among agencies are crucial.

Many experts in the field urge that comprehensive services be provided by interdisciplinary teams at a single site. This concept is consistent with the policy recommended by the National Commission on Infant Mortality.

However, this "one-stop-shopping" approach may not be feasible in many communities. Because of the variety of services required to appropriately serve drug-exposed infants and their families, many community-based agencies often provide these services. Specific agencies in the community can offer a unique approach or focus that might be difficult to achieve in a single agency. Due to lack of effective networking mechanisms among agencies (as well as overburdened workloads), problems often arise when one agency is unaware of services provided by another. For these and other reasons, accessing services from one agency to another can be problematic. As previously mentioned, programs receiving Block Grant monies set aside to treat women and women with dependent children are required by law to provide women and their children with a comprehensive range of services, either directly or through referral.

Thus, when multiple sites are involved, the sites or agencies should carefully coordinate with one another so that needed services are provided without duplication of effort. Case management is crucial in helping to ensure access to appropriate services. Agencies may wish to consider the establishment of structured mechanisms to foster effective interagency communication regarding the provision of services to drug-exposed infants and families.

Other approaches might also be taken into consideration such as home-based nursing and counseling. Access to treatment may be enhanced if services are decentralized and close to the people being served. Easy access to public transportation is important. Decentralized services in the form of home-based nursing and counseling can also facilitate collaboration with CBOs.

Comprehensive health and psychosocial services for drug-exposed infants include substance abuse treatment for the mother, health services, mental health services, social services, and educational, vocational, and employment services. Key features of these services include:

- Cultural competence
- Utilization of outreach workers and community-based organizations
- Accessible, coordinated services with interagency linkage mechanisms
- Nontraditional approaches, such as home-based services.

Treatment For Parents

The best way to help the drug-exposed child is to help the mother (and the father when possible) recover from addiction. Treatment should occur within the context of the mother-child dyad, with particular attention paid to the mother's drug use and its impact on parenting skills. Every effort should be made to include fathers as well as mothers. Treatment should be nonthreatening, nonstigmatizing, and supportive. The treatment team should also work with other siblings and members of the extended family, especially drug-free family members. The treatment team should be culturally competent and well trained and understand how services provided with cultural awareness of the mother's and father's background can play a positive role in recovery.

Pregnant women should not be denied such treatment or have treatment postponed merely because of pregnancy. In fact, since the health and welfare of both the mother and the unborn child are at stake, efforts should be made to give pregnant women priority access to AOD abuse treatment services.

Such priority status is now a requirement for all programs receiving Substance Abuse Block Grant funds. Programs serving an injecting drug use population must give preferential treatment in the following order: (1) pregnant injecting drug users; (2) pregnant substance abusers; (3) injecting drug users; (4) all others.

If the program does not have the capacity to provide treatment services to a pregnant woman, the woman must be referred (with the use of a toll-free number or similar mechanism) to the State. The State is then required to refer the woman to a treatment program that has room to serve her not later than 48 hours after seeking treatment. Thus, the State must have a capacity tracking system to track all open AOD treatment slots available to pregnant women in the State.

Detailed treatment guidelines, including a description of an appropriate continuum of care that includes medical stabilization and detoxification guidelines, are available in the TIP, *Pregnant, Substance-Using Women*. Many of these guidelines are equally applicable to women in the postpartum period.

Treatment should focus on the dual goals of abstinence from drugs and successful parenting. Within the context of AOD abuse treatment programs, parenting skills should be addressed or reinforced. The program and its staff can serve as a secure base from which the mother can try new approaches to parenting, often ones that she did not experience as a child. The treatment component must acknowledge each woman's role as a mother struggling to rear young children. This parenting role must be supported by all staff, who support the mothers in their relationships with their babies and praise their ability to comfort their children, make their children smile, and know when their children are sick. These daily interactions support the mother in her parenting abilities and allow her to feel successful as a good mother to her children. Please refer to [Appendix A](#) for materials on parenting skills.

Maternal Health Services

Mothers of drug-exposed infants must have their basic health needs attended to if they are to function effectively in a parental role. These needs include:

1. Postpartum care.
2. Treatment of other health problems often attendant upon addiction. These health risks are discussed in [Chapter 2](#) and are fully described in the [TIP Pregnant, Substance-Using Women](#).
3. Training in infant care (including breastfeeding, if appropriate).
4. Reproductive health services, including family planning, contraception, and education concerning the increased risk of unintended pregnancy and HIV infection associated with the use of drugs and alcohol. These services should be delivered within the context of the mother's drug counseling to be most effective.
5. Counseling and testing for HIV and other sexually transmitted diseases. Active efforts must be made to direct women who are HIV positive or have AIDS to appropriate services.
6. Educational efforts concerning the effects of illegal and legal drugs, including alcohol and tobacco, on the woman's health, the health of unborn children, and the health of the infant and siblings.

Again, health care services, training, and education should also be provided to the father as much as possible.

Mental Health Services for the Parents

Substance abusers in general, and substance-abusing women in particular, often have coexisting mental health problems that must be attended to during treatment. Necessary services include:

1. Mental health and psychiatric evaluation and treatment services, especially for depression.
2. Assessment and counseling for physical and sexual abuse, and for the possibility of post-traumatic stress disorder.
3. Counseling and training in self-esteem and image enhancement.
4. Training in interpersonal skills.
5. Training in self-sufficiency and independent living (feeding, housing, preparing meals, locating child care, etc.).
6. Relationship training between men and women.

Parental Educational/Vocational Services And Employment Assistance

Parents of drug-exposed infants are often functioning cognitively at the age at which their own drug use first began. Their education and job history may be intermittent at best. In the absence of economic self-sufficiency, drug abuse treatment and other psychosocial services are unlikely to make a permanent improvement in the family's lot. Parents of infants and young children should be a priority for educational/vocational services. Such services should include:

1. Job skills assessment.
2. Graduate Equivalency Diploma (GED) classes.
3. Vocational skills instruction geared to job opportunities in the local area.
4. Employment-related services, such as coaching in interview techniques, preparing employment applications and resumes, mentoring by employed persons, and obtaining and reviewing lists of viable job prospects.

Other Social Services

To round out the services listed above, an assortment of ancillary services may be necessary. These include, but are not limited to:

1. Child care and babysitting services in general, and especially during service visits.
2. Assistance in obtaining safe living arrangements and locations.
3. Public transportation or taxi vouchers for service visits.
4. Family support services and training in parenting skills.
5. Training in life management skills such as personal care, time management, and budgeting skills.
6. Outreach services, which might include any one of the above-mentioned items.
7. Legal services, including counsel in cases involving domestic violence, divorce, child custody, and right to treatment.

Each mother should receive an individual service and care plan responsive to the unique needs of her family. Wherever possible, services should be gender-specific, as well as culturally specific, addressing the particular circumstances of the woman and her children. Services should be designed to aid rather than punish women; to this end, focus groups consisting of addicted and recovering mothers might be convened to share information on what they consider to be particularly useful services. Service providers should also make use of recovering mothers as role models and community-based outreach workers to help with visits, transportation, and support.

Incentives should be offered for successful completion of services, including followup. Such incentives could include: donated infant supplies, infant blankets, diapers, formula, baby furniture, toys and educational toys, and coupons for specific food items.

Finally, service providers should be sensitive to the varied cultural and ethnic backgrounds of women who use alcohol and other drugs, and should therefore tailor services accordingly. Such sensitivity has a significant impact on both service utilization and compliance with the recommended treatment.

Helping Parents or Guardians Obtain Supportive Services

Mothers of drug-exposed infants display a wide variety of needs and problems that affect their lives and those of their children. These include physical and psychosocial factors contributing to their drug use as well as environmental factors harmful to adequate or healthy lifestyles.

Persons providing assistance to mothers of drug-exposed infants can recognize and work to address the barriers to services that face these women. Such barriers include, but are not limited to:

- Lack of alcohol and drug abuse programs for pregnant and parenting women.
- Lack of transportation to and from service providers.
- Lack of child care or babysitting during service sessions.
- Cost of services.
- Insufficient funding available for substance abuse treatment programs directed to pregnant and parenting women, especially programs that are family-centered and include the mother's other children, the father, and the extended family in the treatment process.
- Lack of sufficient programs that are adapted to the cultural, racial, and linguistic characteristics of the women using the services.
- Lack of sufficient programs that are based in the communities or neighborhoods where the women live.
- Nonsupportive or hostile attitudes of service providers toward drug-using women.
- Stigma associated with drug use, especially drug use by women.

- Lack of knowledge by drug-using women concerning the service options available to them.
- Complex and often inconsistent eligibility requirements and application processes that vary by program.
- Fragmentation of services - lack of a single provider or locale where all needed services can be obtained, including comprehensive health and dental services. (This can be a formidable obstacle when the woman and her children face significant chronic medical problems, such as HIV).

In addition to the above-mentioned barriers to services facing mothers of drug-exposed infants, it is important to recognize several essential components in the development of adequate services for this population of women, as outlined below.

1. **Case Management** - An essential element for an effective continuum of care is the case management function. This function can be provided through the auspices of virtually any agency, and is needed by every woman and her family. Case management defines, initiates, and monitors the medical, drug treatment, psychosocial, and social services provided to the drug-exposed infant and its family. Case managers serve as advocates to help the woman and her family negotiate the bureaucracy and qualify for public programs such as Medicaid, WIC (Women, Infant and Children), AFDC (Aid to Families with Dependent Children), food stamps, and housing assistance.

(Please see the section on referrals in [Chapter 3](#), Followup and Aftercare, for an additional listing of public programs.)

The multiple services coordinated by the case manager are generally provided by a variety of agencies. Some of these services are initiated during or even prior to pregnancy, and may continue long after delivery. Drug- and alcohol-abusing women and their children are also typically referred to a consortium of service providers that may change over time, depending on a patient's individual circumstances.

2. **Outreach** - To help pregnant, substance-using women and mothers of drug-exposed children learn about the services available to them, service providers should develop the following:
 - Outreach efforts to culturally diverse populations. At least a portion of outreach services should be conducted through nontraditional means, such as through churches, beauty parlors, laundromats, and other social settings. Outreach workers must be sensitive to the racial, ethnic, cultural, and socioeconomic concerns of those being served.
 - Public service announcements (PSAs) advertising services available and aired on radio or TV stations that are popular with groups targeted for services.
 - A 24-hour, toll-free hotline for service information and referrals.
 - Videotapes about services that can be used by community and church groups.
 - Pamphlets advertising the services available.

The outreach worker is crucial to a program's ability to effectively carry out these outreach efforts.

 - **Affordability** - Discussed below are a number of considerations from the viewpoints of both the patient and the health care facility that can help to ensure that comprehensive services are affordable to all women and families in need of such services.

Keeping Families Intact

A comprehensive and individualized assessment of the family's needs may prevent inappropriate placement of drug-exposed infants and children in foster care. To achieve the goal of keeping families intact, the drug-exposed infant and his or her family should have access to the following services:

- Availability of case manager services on a 24-hour, on-call, basis
- Quality day care
- Individual / family counseling and crisis counseling
- Housing assistance and emergency shelters
- Procedures and arrangements for access to emergency financial assistance
- Arrangement for provision of temporary or respite care

- Availability of outreach workers who may be able to visit the woman and her family in her own environment.

A new program in New York City provides intensive supervision and counseling to substance-using women who have been permitted to take their babies home from the hospital. Under the program, social workers visit families at least once a week to help ensure that mothers remain in treatment and assist them in other areas, including health care for the infant and housing and other social services (Treaster, 1991).

Referral to Child Protective Services

In most jurisdictions, child welfare services are responsible for a broad array of activities including preventing unnecessary separation of children from their families, restoring children who have been removed from their natural families through provision of appropriate services, placing children in suitable adoptive homes in cases where reunification with the biological family is inappropriate, and assuring adequate care of children not living with their families.

Within the child welfare system, child protective services (CPS) is the administrative unit responsible for investigating allegations of abuse and neglect. The focus of CPS is on strengthening and empowering families who are at risk of child abuse and neglect; removing children from their homes is seen as a last resort when continued work with the family has failed.² Regarding the referral of a drug-exposed infant to child protective services, the following guidelines are offered:

1. **Reasons for referral** - Prenatal drug use or a positive drug test should not be an adequate reason in and of itself for referring an infant to CPS. Referral should be made only when there is some question about the health and safety of the child. However, in some States, by statute, evidence of drug exposure or a positive urine toxicology is, by itself, grounds for making a child abuse report. Therefore, although a mother's presumed drug use is not an adequate reason for an infant to be referred to protective services, referrals are sometimes made on this basis.
2. **Placement decisions** - The decision to remove the child from the home should be made if a child is endangered or if the parents cannot adequately provide for the child's health and welfare. Such decisions should be made only after thorough assessment of the infant's family situation. The mother's ongoing substance use, by itself, should not be a criterion for mandating removal from the home. Occasional relapse is a normal part of the recovery process and, as such, should not be the sole criterion for removing the infant from the home. By both Federal and State law, child welfare agencies must make "*reasonable efforts*" to prevent the removal of a child from his or her parents through the provision of services for the family, unless a child would be endangered even with the provision of such services. In some jurisdictions, the caseloads of child protective workers are so large that the goal of strengthening and empowering the family has been difficult, if not close to impossible, to achieve.
3. **Placement with relatives** - If the child is to be removed from the mother, the first priority should be to place the child with responsible grandparents or other family members, rather than making an immediate placement to foster care. This recommendation should be tempered by the realization that a large proportion of substance-using mothers may themselves be children of substance-using parents. Placement of an infant with grandparents or other family members who have problems with AODs is clearly inappropriate. However, where appropriate, placement of a child with family members can result in significant benefits to the child. Such a placement may be less disruptive and stressful because the child is not separated from family.
4. **Special programs and funding for drug-exposed children** - Because foster care systems are receiving increasing caseloads of drug-exposed children, there is a necessity to develop special training and other programs for meeting their needs. In addition, special funding should be procured to help meet the increased costs incurred by the adopting parents of drug-exposed infants. Most drug-exposed children qualify as "special needs" children. Both foster and adoptive parents may be able to receive special subsidies to help care for the child. In addition, children in foster care receive Medicaid, and Medicaid follows the child after adoption. Thus, children who were Medicaid-eligible before

adoption can continue to be eligible to receive Medicaid after adoption, up to adulthood. However, it is a good idea to obtain verbal and written agreements regarding both the special needs subsidy and Medicaid eligibility before the adoption or foster placement is finalized.

5. **Foster placement** - Given the specialized needs of the drug-exposed infant, efforts should be made to develop special foster homes with a limited number of children placed in such homes. (Child welfare agencies often provide special foster homes and / or residential facilities with additional financial reimbursement and other support.)
 - a. **Family reunification** - If an infant is placed in foster care, the ultimate goal should be reunification with the mother at the earliest possible time, as soon as the health and safety of the infant and mother can be assured, in the best judgement of the caseworkers. This goal should be clearly communicated to foster parents. It must also be acknowledged that reunification may not be possible or practical based on the best interests of the child.
 - b. **Stability** - Wherever possible, serial foster care placements of *any* infant should be avoided. Such placements weaken an infant's ability to bond with caretakers and threaten his or her emotional, physical, cognitive, and social development, with effects often lasting into the adult years.

Followup of Infants In CPS or Foster Care

The recommendations in this section are built upon those found in [Chapter 2](#) on followup and aftercare services for infants, and are focused on the psychosocial needs of the infant.

1. **Case management** - Followup services for drug-exposed infants and children in foster care should be provided using a case management model. The advocate for the infant could be a public or private case manager, a community caseworker, an outreach worker, or a recovering woman working under direction of a designated case manager. The continuing assessment and treatment needs of infants placed in foster care can be met best through case conferences, where all allied professionals provide input into the service needs of the infant and family. Telephone case conferences may be an expedient method for achieving this goal.
2. **Training** - Ongoing training should be provided to all service providers working with drug-exposed infants and their foster families. Such training should include information about the effects of drug and alcohol use in general, information concerning the child protective services system, and information concerning the unique service needs of the drug-exposed infant. Initial and ongoing training should also be conducted on HIV-related issues. Foster parents themselves and other caregivers need to receive special training regarding the unique needs of drug-exposed infants and mothers. In particular, they should be trained to provide stimulation to the infant at a level appropriate for that particular infant.
3. **Reunification** - Foster parents should be made aware that the ultimate goal of child protective services is to reunite the infant or child with the biological family, whenever possible.
4. **Attitudes toward substance use** - Child protective service caseworkers and foster parents should evaluate their attitudes about substance-abusing women as well as their own use of substances, including alcohol and tobacco, and the example it provides to children placed in their care. Ongoing training and values orientation should be provided to caseworkers and foster parents as much as possible.

Assuring the Quality of Services For Infants in Foster Care

Quality assurance standards for child protective services, foster care agencies, and foster parents are important to ensure adequate and appropriate levels of care for drug-exposed infants in foster care. Standards of practice must be reviewed and updated on a regular basis.

Such quality assurance standards should include but not be limited to:

1. **Caseload limits** - In the current era of escalating social service needs and shrinking budgets, child welfare workers are often forced to handle ever increasing and complex caseloads, prohibiting the provision of effective child protective services. Administrators and service providers working with drug-exposed infants and their families should be familiar with public and private child welfare standards, which seek to address quality assurance issues such as caseload size. Both the private and public sectors are involved in the establishment of standards or goals for practice in the field of child welfare services. For example, the Child Welfare League of America (CWLA) develops and publishes child welfare standards to be used in planning, organizing, administering, and improving services; in establishing State and local licensing requirements; and in determining the requirements for accreditation. These standards include the development of recommended caseload and workload ratios for different types of services. (For example, in the area of child protective services needed for abused or neglected children and their families, CWLA standards describe the recommended number of active and new cases per month per social worker and the recommended ratio of supervisors per social worker.) Licensing provides basic protection for the well-being and protection of children. Through the licensing of child-placing agencies, residential group care facilities, foster family homes, and child day care facilities, States exercise their power to protect children.³
2. **Number of infants or children per foster home** - Child welfare agencies establish standards regarding the maximum number of high-risk infants to be placed in a foster home or residential facility. Drug-exposed infants in need of placement should be assessed to determine the intensity of services required to adequately care for the child. Due to inadequate staffing of child welfare agencies, established standards are not always followed and placement assessments are not always accurate. Programs serving drug-exposed infants should work closely with the child welfare agency to help guarantee that an appropriate foster care placement has been made.
3. **Recruitment and training of foster parents** - Agencies should be able to show evidence of ongoing recruitment of foster parents willing to accept drug-exposed infants. Prospective foster parents should receive special training concerning unique needs of drug-exposed infants. Training will also be needed regarding HIV infection and drug-exposed infants.⁴
4. **Interagency agreements** - Foster care agencies should develop memoranda of agreement with other service agencies to coordinate and avoid duplication of services to drug-exposed infants and children. These agencies should hold quarterly meetings to review existing standards, resolve problems, and recommend changes. Within the consortium of agencies, a single agency should be assigned responsibility for quality assurance compliance.
5. **Foster parent review** - The case plan of a drug-exposed infant placed in foster care should be reviewed every 6 months, with a mandatory home visit within the first month of foster care.
6. **Cultural issues** - Extensive efforts should be made to recruit foster parents from the same racial and cultural backgrounds as the infant. Effective efforts in this arena usually require extensive engagement with the community in the recruitment process. For example, ongoing or periodic foster home recruitment campaigns can be launched in coordination with local churches, sororities and fraternities, the media, civic organizations, and other grass-roots organizations familiar with the cultural nuances within the community. Many such organizations are eager to help recruit foster homes from the same racial or cultural background as the infant in need of placement. However, in addition to extensive community-based recruitment campaigns, consideration might be given to relaxing regulations that require placement of infants with parents from the same racial background. Such measures should be considered only when other efforts have failed to ensure the placement of drug-exposed infants in qualified foster homes. Such foster parents should receive initial and ongoing training around the need to understand and respect the racial and cultural background of the infant.
7. **Followup surveys of client satisfaction** - Followup surveys should be conducted with the biological parent(s), the foster parents, and the coordinating agencies to determine their satisfaction with the process and any recommendations for improvement.
8. **EAPs for professional and volunteer workers** - Employee assistance program components should be mandated and integrated into all agencies involved in child placement and foster care services. This will provide treatment and counseling services to caseworkers and other service providers who may themselves be substance users or abusers.
9. **Professional attitudes and behavior** - All professionals working with drug-exposed infants and their mothers and families should examine their own knowledge, attitudes, and behaviors regarding use of drugs, alcohol, and tobacco and should receive ongoing training on these subjects.
10. **Stress management** - Stress management training must be provided to workers involved in the care of drug-exposed infants and their families. Likewise, sensitivity training should be provided to caseworkers concerning their attitudes and behavior toward drug-using women so that a nonpunitive,

supportive approach is maintained. Foster parents with drug-exposed infants also need stress management and sensitivity training. Whenever possible, such programs should be provided for these caretakers.

Chapter 5 - Ethical and Legal Guidelines

This chapter includes specific guidelines in the following areas: assessment of mothers and newborns; confidentiality of information about treatment for drug and alcohol abuse; issues arising during postneonatal followup of the drug-exposed infant; and training in ethical and legal issues. However, throughout this chapter, it should be kept in mind that AOD addiction is fundamentally a medical, not a legal, issue.

As a foundation for these guidelines, the following principles are enunciated:

1. The ethical principle of respect for persons makes the woman the autonomous decisionmaker for herself and her fetus, which is undeniably part of her body. A pregnant woman and her fetus ought to be thought of as a unit, or dyad, and intervention strategies during pregnancy ought to benefit both the woman and the fetus.
2. The ethical principle of beneficence requires an individual to act in a manner that maximizes good consequences and minimizes harm to another. Women who are pregnant have obligations of beneficence to their fetuses.
3. Society in general, and health care professionals in particular, have obligations of beneficence to both the woman and fetus as well as the preservation of the family. These obligations include provision of comprehensive, multiservice, community-based, gender-specific programs that are accessible and affordable.
4. Involuntary civil commitment, criminal prosecution, or use of civil child protective service interventions for a pregnant woman, ostensibly to benefit the fetus, should not be used. Decisions concerning the incarceration of a pregnant, substance-using woman should be made only on the basis of an offense, and should not be related to pregnancy and substance abuse. If a pregnant, substance-using woman is incarcerated, adequate drug treatment and all necessary medical care must be provided.
5. If a pregnant, substance-using woman is eligible for a diversion program for a crime unrelated to drug use during pregnancy, this alternative should be encouraged and should provide comprehensive, gender-specific, multiservice treatment to enhance the health of the woman and the development of the fetus.
6. After birth, intervention strategies should continue to be designed to benefit the mother-infant dyad. There should be a strong presumption in favor of maintaining the mother-child relationship, and the right of the mother as decisionmaker for the child, unless the mother is not acting in the best interest of the child.
7. Treatment for the father of a drug-exposed infant should be available in the same program when appropriate, or in a different program. It may be therapeutically contraindicated for the parents of the drug-exposed child to receive treatment in the same program. For example, if the mother is engaged in treatment and is drug free while the father continues to use drugs, it is probably more appropriate for the father to be in a different treatment program. If the father is substance-using himself, then treatment should be made available to him as well. Every effort to strengthen and maintain the family as a unit should be considered in providing services to the pregnant, substance-using woman and the mother-infant dyad.
8. In designing programs and providing services, agencies and individual providers must adhere to Federal and State laws. Because these laws are subject to change, programs and services need to be reviewed periodically by the provider's legal counsel.

Assessment of Mothers and Infants for Drug Use / Drug Exposure

Mothers

Health care professionals, hospitals, and clinics have an obligation to identify and assess all women, optimally during prenatal care, but at least at the time of delivery, for substance use.

1. Assessment should include the father and the family context.
2. Identifying a woman as a substance user does not, by itself, imply an obligation to report to child protection or law enforcement agencies. (State laws may differ in this regard.)
3. Maternal use of a substance does not equate to child abuse *per se*.
4. Assessment should include providing the woman with information regarding her right to confidential or anonymous HIV counseling and testing. Providers involved with the substance use assessment process should receive initial and ongoing training in HIV concerns, and should be able to present the woman with arguments regarding why knowledge of her HIV status may be beneficial to herself and her child. However, assessors must also understand that HIV testing is voluntary, that women have the right to refuse to be tested for HIV, and that this right to refuse testing must be respected. (HIV testing of the infant involves medical and legal questions beyond the scope of this TIP. Suffice it to say that, when the mother has custody of her infant, her informed consent is required for the infant to be tested.)

Guidelines for urine toxicology were developed for a companion volume in this series, *Pregnant, Substance-Using Women*, and appear in [Appendix C](#).

Infants

Health care professionals, hospitals, and clinics have an obligation to assess newborns who exhibit signs and symptoms of drug exposure, whose mothers have been identified as probable substance users, or whose mothers have signs and symptoms of drug use.

1. Identifying an infant as drug exposed should not, by itself, imply an obligation to report to child protective services or law enforcement agencies. (State laws may differ in this regard.)
2. The finding of substances in the newborn's urine does not equate to child abuse by his or her mother. (State laws may differ in this regard.)
3. Screening of the newborn's urine should be done only for purposes of medical diagnosis and treatment, and should be accompanied by communicating with and informing the mother. As discussed in [Chapter 2](#), in certain circumstances testing infants is medically necessary for the proper and safe care of the infant. Specific informed consent of the mother is not required because of the importance of the medical information to the care of the infant and the fact that delay in obtaining the specimen would cause invalid results due to the short time in which drugs may be detected in the urine.

Reporting Laws And Laws Governing Confidentiality

Many jurisdictions require that drug abuse by pregnant women and / or substance exposure in an infant be reported to authorities. This sometimes poses a dilemma to hospitals, clinics, and treatment programs, which must also follow Federal regulations concerning the confidentiality of alcohol and drug abuse patient information (42 CFR Part 2). Federal laws take precedence over State laws, except in cases where child abuse is concerned. Since 1986, a law has been in effect declaring that the State's child abuse laws should be adhered to in the area of child abuse. Hospitals, clinics, and treatment program staff must be aware of their State's laws, regulations, and reporting requirements (e.g., with respect to mental health, HIV, and child protection). Likewise, patients in treatment programs should be told what confidentiality protection their program offers, and when these protections may be suspended. For instance, a program can be subpoenaed

to release confidential treatment records or be required by State law to report drug use by a pregnant woman or the mother of a drug-exposed infant.

Confidentiality and reporting laws and regulations have a significant impact on service providers. The challenge is to design a treatment program that complies with Federal and State laws and regulations, and at the same time provides services that are responsive to the special needs of pregnant, substance-using women and families of drug-exposed children. Treatment program staff must be trained to deal with the conflicts between confidentiality and reporting issues, and to recognize how these conflicts affect their ability to deliver services.

Impact of Reporting Laws On Substance-Abusing Women

State and local laws requiring that maternal substance abuse and / or fetal drug exposure be reported to authorities have a significant impact on pregnant women, mothers, and their children. Such a report could provide impetus for removing children from their mother's care and putting them in protective custody or in foster care. Knowing that such a report was in the offing, the woman might forego her prenatal care or the followup care provided to her and her infant.

The following guidelines explain Federal regulations on confidentiality of drug and alcohol referral and treatment information and can assist programs in their efforts to design effective and appropriate procedures for treating pregnant, substance-using women and mothers of drug-exposed infants.

1. Prohibition of Disclosure - What follows is a summary explanation of the Federal confidentiality regulations, called the General Rule Prohibiting Disclosure:
 - Except under certain limited conditions, Federal confidentiality regulations prohibit the disclosure of records or other information concerning any patient in a Federally assisted alcohol or drug abuse program (42 CFR, Secs. 2.12; 2.13(a)).
 - This prohibition of unauthorized disclosure applies whether or not the person seeking information already has the information, has other means of obtaining it, enjoys official status, has obtained a subpoena or warrant, or is authorized by State law (42 CFR, Secs. 2.13(b); 2.20).
 - Any State provision that would permit or require a disclosure prohibited by the Federal rules is invalid. However, States may require greater confidentiality than the Federal regulations (42 CFR, Sec. 2.20).
2. Exceptions - Although the general rule is that patient-identifying information may not be disclosed, the regulations set out a number of conditions permitting limited disclosures upon patient consent, and a few circumstances in which disclosures may be made without patient consent. Each of these conditions or circumstances has its own requirements and limitations. In general, permitted disclosures fall into the following categories:
 - Disclosures made with written informed consent of the patient
 - Disclosures made pursuant to internal program communications
 - Disclosures made in response to a court order
 - Disclosures made pursuant to a crime at the treatment program or against program personnel
 - Disclosures made for research or audit purposes
 - Disclosures made when an individual is obligated by State law to report reasonable suspicions of child abuse or neglect
 - Disclosures made pursuant to a qualified service organization agreement
 - Disclosures made pursuant to a medical emergency.

A medical emergency is defined as a situation in which:

- The individual's life is in immediate danger without emergency treatment, and
- He or she is unable (for example, unconscious) or incompetent to give consent, and
- The person authorized by law to give consent for the individual is unavailable.

Issues Arising During Postneonatal Followup

During postneonatal followup of the drug-exposed infant, the following should be noted:

1. Caregivers need to be aware of their own attitudes and feelings regarding substance-using women of childbearing age, because attitudes and feelings may hinder the ability of the provider to form a therapeutic alliance. A successful treatment intervention for the mother of a drug-exposed infant demands a therapeutic alliance between mother and provider, and should include: a nonjudgmental, nurturing approach; honest and open communication; and clear and concise shared expectations. Moreover, the provider of care should be aware of the complex psychosocial environment of drug-using women. This environment may include poverty, domestic violence, sexual abuse (including incest), homelessness, depression and other coexisting psychiatric disorders, intergenerational history of substance use, and the absence of healthy parenting.
2. Since chronic substance use is recognized as a relapsing disorder, programs and providers should:
 - Develop policies and procedures to keep patients in treatment, work with relapsing mothers, and foster the mother-infant dyad.
 - Recognize critical periods and issues of relapse and develop strategies to support the mother and protect the infant through relapse episodes. Relapse alone should not be grounds for reporting to a child protection agency, or for placing the child in foster care.
 - Be aware that the safety and well-being of the infant need to be protected. Notwithstanding the confidentiality requirements and the therapeutic alliance with the mother, a report to child protective services may be necessary and even legally required if the mother's substance use is seriously impairing her parenting ability.¹
3. In dealing with drug-exposed infants, successful treatment of the mother-infant dyad requires that agencies and providers of care:
 - Establish interactive working relationships in order to coordinate all aspects of care.
 - Develop mechanisms so that case-specific information can be shared while respecting confidentiality and with appropriate informed consent.
 - Provide comprehensive services that include, but are not limited to:
 - Medical care for mother and infant, including acute care, well baby screens, immunizations, developmental assessment and followup, preconception counseling, and necessary medications.
 - Mental health care including alcohol and other substance use treatment, family therapy, and identification and treatment of coexisting psychiatric disorders.
 - Psychosocial interventions including parenting training, child development education, anticipatory guidance, assistance in obtaining public benefits, protection from domestic violence, child care, education, and vocational and job training.

Training in Legal And Ethical Issues

Groups, agencies, and individuals caring for a drug-exposed infant must clearly understand and address all aspects of the complex legal and ethical issues involved, so as to achieve the best possible care and positive outcome for the infant.

In order to ensure a positive outcome, all staff involved with a drug-exposed infant should participate in comprehensive and continual training that covers every aspect of the recommendations presented in the preceding sections. This training should be developed at the Federal level in collaboration with the States, and should include specific examples illustrating how the recommendations can be applied in a variety of environments and circumstances.

1. The first level of training should be provided by the Federal Government to staff of State health and social services departments. Once trained, these staff will become better able to evaluate and recommend improvements to institutions and programs serving drug exposed infants.
2. The next level of training will be delivered by States to local municipalities, so as to inform local service providers of new or clarified guidelines concerning the care of substance abusing women and their

infants. In addition to providers of health and social services, persons who interface with and are involved in the court process should receive training. Judges are a priority target group for training. Attorneys, probation officers, and other court personnel should be encouraged to participate in training. Training should be made available to any person involved in making decisions for drug-exposed infants and their families. Cross-training of groups encompassing health professionals, child welfare specialists, and judges and attorneys involved in family law is particularly encouraged.

3. The final level of training must occur at the local level and target specific agencies involved in the care of substance-abusing women and their drug-exposed infants. This training must also include the necessary tools for documenting overall compliance with the guidelines.
4. Training at all levels must be ongoing and updated at regular intervals to provide the most up-to-date information - including any changes that may occur in the law and these guidelines - to all groups, agencies, and individuals involved with care of substance-abusing women and their infants.
5. New training dollars should be made available at the Federal level to ensure compliance with these guidelines.

Endnotes

¹ The Panel on Psychosocial, Legal, and Ethical Issues suggests that these recommendations be added to the draft *TIP on Pregnant, Substance-using Women*, Chapter 2, Postpartum Guidelines.

Chapter 6 - Quality Assurance Guidelines

Treatment programs have increasingly focused on quality assurance (QA) and improvement techniques as means to maintaining or improving the quality of care, while addressing the problems caused by rapidly escalating service costs. Because QA has often been mandated for reimbursement and licensure, this TIP assumes that treatment programs have an active QA program. The following, therefore, are suggestions for important areas for monitoring in programs that provide treatment for drug-exposed infants. These suggested areas alone should not be considered a complete QA program.

As noted in the previous protocols, the importance of linkage and collaboration is paramount for programs addressing treatment of drug-exposed infants. Entry into treatment can come from a variety of programs in the service continuum, requiring referral to other providers to ensure successful treatment. Therefore, several linkage areas are important for QA monitoring:

- Documentation of referrals, sharing of information, and ensuring that linkages are made;
- Compliance with Federal and State guidelines for confidentiality; and
- Interagency agreements that clearly indicate responsibilities of each program.

The new Substance Abuse Block Grant regulations include many requirements regarding linkages, quality assurance, interagency agreements, and monitoring of these activities. Thus, AOD treatment programs receiving these funds will be greatly assisted by adhering to the quality assurance guidelines discussed in this section.

Documentation of Referral to Ensure Linkage

These guidelines are predicated on the concept of a continuum of care, based upon drawing from many community-based services. Experience has shown that merely making referrals ensures neither that services are received nor that the service provided is of high quality. Therefore, it is one of the functions of a QA program to monitor linkages to referral sources. A well-designed QA program will routinely monitor a sample of

all patient records and all referral sources to ensure linkage. Results of monitoring and actions taken to correct problems and improve service must be documented. Some examples of monitoring are:

- Monitoring patient records to ensure that proper referrals were made.
- Monitoring to ensure that all appropriate and necessary information is shared with the referral agency (such as reason for referral and problems to be addressed).
- Monitoring of referral logs, payment vouchers, or other referral documentation (such as payment appropriate to services provided).
- Monitoring patient records to ensure that there is documentation of linkage (such as documentation that infant was evaluated and accepted for services).
- Monitoring patient records for notes of treatment progress and / or continued service (such as regular documentation of treatment progress).
- Documentation that services are no longer needed (such as documentation of why services are no longer needed and what aftercare services are being provided).

Compliance with Federal Guidelines For Confidentiality

Since confidentiality regulations vary among the States (State regulations can be more stringent than Federal regulations), it is important that each agency ensure that internal policies are in compliance with both Federal and State regulations on confidentiality and patient records. Once compliance is ensured through the development of agency confidentiality policies, a process of QA monitoring can be developed that routinely reviews a sample of all program records. The results of monitoring and actions taken to correct problems and improve service must be documented. Some examples of monitoring are:

- Ensuring that there is documentation of providers informing patients of their right to confidentiality, and to information concerning laws relating to court involvement.
- Ensuring that there is documentation that providers inform patients of all laws as they relate to all areas that affect individuals who are receiving services.
- Ensuring that there is a written informed consent on file whenever there are discussions concerning the patient with individuals or organizations outside the treatment facility.
- Ensuring that the written informed consent is time-limited, content-specific, person-to-person, signed, and witnessed. A sample consent form is included; see [Exhibit 8](#).

Interagency Agreements

For interagency collaboration and linkage to be successful, a written document is needed that clearly delineates the responsibilities of each program to ensure service delivery. Interagency agreements should not only indicate the services to be provided, but should also state the referral process and the documentation requirements of both agencies. Interagency agreements should be reviewed by participating agencies on a regular basis and modified as necessary. Findings from data collection should be taken jointly. Results of monitoring, as well as actions taken to correct problems and improve service, must be documented. Some examples of monitoring are:

- Ensuring that the referring agency has provided all appropriate and necessary patient data to the referral agency.
- Ensuring that there is documentation that the referral agency has provided all agreed-upon services in a timely manner.
- Ensuring that the referral agency provided to the referring agency documentation of patient progress, continued need for services, or readiness for termination of services.
- Checking any important specific parts of the agreement required to maintain the continuity of care.

Other Important Areas for Monitoring

As noted above, because of the importance of continuity of care in this model for treating drug-exposed infants, the areas of linkage and collaboration should be paramount in designing quality assurance monitoring. The following are more examples for monitoring:

- Ensuring linkage through the acceptance of patients for treatment.
- For the patient not accepted for treatment, ensuring that there is proper documentation of the reasons why the patient was not appropriate for the facility, and that steps were taken to link the patient to appropriate services.
- Although discharging pregnant patients is not recommended, occasions may arise that necessitate this course of action. In these cases, there must always be full documentation of the rationale for discharge and prior attempts to engage the patient in treatment. Similarly, there should be documentation of referring the patient to alternative treatment.
- Ensuring that there is documentation of referral and linkage to appropriate programs if the agency is unable to provide necessary services.
- Checking to determine if the primary treatment facility monitors whether patients have a treatment plan listing all required services, whether there is documentation that the patient is linked to all required services, and whether there is documentation of the patient's progress in all referred services.

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Appendix A - Resources

Information Resources on Drug-Exposed Infants

This Appendix provides a listing of resources - including national organizations, special reports, manuals, and books - with general information on drug-exposed infants. Although there are listings which are meant to be of help to professionals, many of the resources listed will assist caretakers of drug-exposed infants - including natural, foster, or adoptive parents - with parenting skills. The Appendix ends with a listing of simple, straightforward strategies and techniques for caring for young children.

SECTION I: NATIONAL ORGANIZATIONS

The following organizations can be contacted by phone or mail for an updated listing of materials or referrals. Please note that the CSAP National Resource Center listed below provides an extensive information and referral service which should be quite helpful to parents, caretakers, and others throughout the United States.

Center for Substance Abuse Treatment (CSAT). Division of State Programs, Rockwall II Building, 10th floor, 5600 Fishers Lane, Rockville, MD 20857, (301) 443-3820. CSAT publishes a range of material on AOD treatment, such as this TIP. CSAT is also the agency to contact for information on the new regulations regarding the Substance Abuse Prevention Block Grants. These regulations include important requirements relating to the AOD treatment of pregnant women and women with dependent children.

Center for Substance Abuse Prevention (CSAP) National Resource Center for the Prevention of Perinatal Abuse of Alcohol and Other Drugs: 9300 Lee Highway, Fairfax, VA 22031, (703) 218-5600 or (800) 354-8824. Commonly called the Perinatal Resource Center, this Center was established by CSAP in 1991 as a training, technical assistance, and information source for people working with the problem of AOD use and maternal and child health issues. Each of its specialized services are described below.

Information and referral services: The Center provides extensive telephone-based information and referral services to people working with the problem of drug-exposed infants. The Center publishes a quarterly newsletter and prepares resource packets and monographs on specific issues.

Perinatal Research and Education Management Information System (PREMIS): PREMIS is a state-of-the-art computer system maintained by CSAP's National Resource Center with up-to-date information on topics related to perinatal AOD use.

Community Team Training Institute (CTTI): CTTI trains interdisciplinary and interagency teams from a cross section of community-based organizations and local government agencies working on the problem of perinatal AOD use. Teams are selected through a competitive application process.

Technical assistance: The Center provides practical hands-on technical assistance to States, communities, and professionals to foster innovative prevention strategies and programs.

Children's Defense Fund: 25 E Street, N.W., Washington, DC 20001, (202) 628-8787. This organization does lobbying, research, and policy reports regarding children, especially the poor, minority, and the handicapped.

Child Welfare League of America (CWLA): 440 First Street, N.W., Suite 310, Washington, DC 20001-2085, (202) 638-2952. CWLA is a national membership organization of more than 700 public and private child welfare agencies that work with children and their families on critical issues such as child abuse, teen pregnancy, adoption, and foster care.

The Clearinghouse for Drug-Exposed Children: Division of Behavioral and Developmental Pediatrics, University of California, San Francisco, 400 Parnassus, Room A203, San Francisco, CA 94143-0314, (415) 476-9691. The Clearinghouse is a resource, referral, and information center serving at-risk children and families in the San Francisco Bay area. It also publishes information resources for people across the country. The Clearinghouse is affiliated with the Division of Behavioral and Developmental Pediatrics at the University of California, San Francisco, Medical Center, devoted to the multidisciplinary assessment and treatment of children.

The Clearinghouse provides a range of services designed to provide basic information about the effects of drug exposure on children's development so that parents, grandparents, teachers, and other caretakers can better understand how to care for these children and help them develop to their full potential.

The Clearinghouse for Drug-Exposed Children Newsletter, published quarterly, contains valuable information for parents, caretakers, and professionals, including policy updates and a list of recent articles on drug-exposed infants.

The ERIC Clearinghouse on Handicapped and Gifted Children: The Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589, (703) 264-9494.

Fetal Alcohol Network: 158 Rosemont Avenue, Coatesville, PA 19320-3727, (215) 384-1133. Contact Linda and Hank Will regarding monthly newsletter and parent support line; no charge to parents of child with FAS or FAE.

Institute on Black Chemical Abuse: 2616 Nicollet Avenue, South Minneapolis, MN 55409, (612) 871-7878. Request a free catalogue on numerous manuals, articles, and reports on substance abuse issues impacting the African American community.

La Leche League International: 9616 Minneapolis Avenue, Post Office Box 1209, Franklin Park, IL 60131-8209, (708) 455-7730. A worldwide organization dedicated to offering information and encouragement (through personal support) to women who want to breastfeed their babies.

March of Dimes Birth Defects Foundation: 1275 Mamaroneck Avenue, White Plains, NY 10605, (914) 428-7100. The March of Dimes is involved with the prevention and treatment of birth defects and infant mortality through education, research, and advocacy.

National Association for Perinatal Addiction Research and Education (NAPARE): 11 East Hubbard Street, Suite 20C, Chicago, IL 60611, (312) 329-2512. NAPARE is a center for research into the problems of perinatal addiction and perinatal AIDS, and the long-term outlook for infants and their families. The mission of NAPARE is to offer leadership in the development of multidisciplinary programs for the prevention and treatment of alcohol and other drug use in pregnancy. A goal of NAPARE is to provide a national network among professionals for the exchange of ideas regarding prevention and intervention.

National Black Child Development Institute: 1023 15th Street, N.W., Suite 600, Washington, DC 20005, (202) 387-1281. NBCDI is dedicated to improving the quality of life for African American children and youth, providing workshops and resources on a range of issues. Send for free catalogue of materials on a variety of subjects relating to children, drugs, parenting, and health concerns.

National Clearinghouse for Alcohol and Drug Information (NCADI): P.O. Box 2345, Rockville, MD 20852, (301) 468-2600 or (800) SAY-NO-TO (DRUGS). The National Clearinghouse is the information component of the Center for Substance Abuse Prevention (CSAP) of the U.S. Department of Health and Human Services. NCADI provides telephone-based information on many publications, organizations, and prevention activities throughout the country.

National Coalition of Hispanic Health and Human Services Organizations (COSSMHO): 1501 16th St. N.W., Washington, DC 20036, (202) 387-5000. COSSMHO is unique in its focus on the health and psychosocial well-being of Hispanic populations throughout the U.S. COSSMHO has literature and information on family-oriented health and substance abuse services throughout the country for the Spanish-speaking community.

National Coalition on Alcohol and Drug Dependent Women and Their Children: 1511 K Street, N.W., Suite 926, Washington, DC 20005, (202) 737-9122. This organization develops literature, sponsors workshops, and works to influence public policy for the prevention of drug and alcohol abuse among pregnant women.

National Committee for the Prevention of Child Abuse: 332 South Michigan Avenue, Suite 1600, Chicago, Illinois 60604, (312) 663-3520. Request a free catalogue of materials regarding a variety of issues targeted to parents, children, teachers, and treatment specialists. Materials also available in Spanish.

National Council of Juvenile and Family Court Judges (NCJFCJ): P.O. Box 8970, Reno, NV 89507, (702) 784-6012. The National Council is a membership organization of the nation's juvenile and family court judges dedicated to improving standards, practices, and effectiveness of courts having jurisdiction over children and families through continuing education programs, research, technical assistance, and publications, as described below.

Continuing judicial education: The Council offers continuing education for judges and related court personnel on issues related to juvenile and family law, conducting over 100 yearly educational programs throughout the country. The educational programs, covering topics such as child abuse and neglect and substance abuse, range in size from large conferences of more than 1,000 persons to as few as 15 judges.

Substance abuse project: In 1990 and 1991, a Forum on Drug-Exposed Women and Their Infants was cosponsored by the Council and CSAP. The final report will be available soon, with further followup reports anticipated, providing judicial response to the problems of drug-exposed infants and their mothers. The Council states that substance abuse is the underlying factor in 60 to 90 percent of all court cases referred to juvenile or family courts. Thus training programs and continuing education on this problem are a priority.

Appendix B - Sample Programs

Sample Programs of Comprehensive Services for Substance-Using Women and Drug-Exposed Infants

This Appendix includes: 1) an outline of what to look for when trying to locate and / or assess programs serving substance-using women and drug-exposed infants; 2) suggestions on how to locate treatment programs for substance-using women and their children in a particular area; and 3) a description of selected comprehensive treatment programs that accept substance-using women and their children. The majority of the programs are residential.

One fact is crystal clear: *There is a critical need for more programs to serve the increasing number of substance-using women and their children.*

A. What to Look For ¹

Here are some guidelines on what to look for when assessing whether a specific program for substance-using women and their children is comprehensive.

1. Programs Should Be Comprehensive

As many services as possible should be offered at one site or effectively linked to existing services in the community. To meet the complex and extensive treatment needs of this population, programs must provide:

- Legal advocacy
- Child protective services
- Prenatal medical care for women
- Pediatric care for the infant
- HIV testing and counseling
- Preconception education and family planning services
- Womens' chemical dependency treatment
- Education and job training
- Coordination of social services
- Developmental assessment of children
- Child care
- Case management
- Parenting education
- Mental health services
- Support groups
- Transportation
- Housing
- Domestic violence counseling.

2. Programs Should Be Confidential and Accessible

Substance-using women are often distrustful of social service systems and "helping" agencies because they fear criminal reprisals, moral judgements, and loss of their children to protective services. Programs must therefore ensure confidentiality and accessibility in order to be effective and inviting to women. Barriers to participation such as lack of child care or transportation must be eliminated.

3. Programs Must Be Collaborative and Coordinated

Collaboration among professionals from different disciplines is recommended. To meet the large number and variety of treatment needs of these patients and to assure integration and avoid fragmentation of services, professionals must clearly define and coordinate their roles. Collaboration is recommended among the many agencies often concurrently serving these women and their families. To provide a unified and coordinated approach among agencies, case management must take place.

4. Interventions Must Be Intensive

The problems of these women - lack of healthy social support systems, the disease of chemical dependency, and parenting infants with behavioral difficulties - require an intensive program response. Programs must make a long-term commitment to clients, and staff should be readily accessible and have frequent contacts with clients. Practical recommendations for creating intensive interventions include home visits, the use of drop-in centers, and crisis telephone lines operating on a 24-hour basis.

5. Programs Must Have a Supportive Orientation

Women in these programs are often emotionally fragile and vulnerable. Interventionists who forge supportive therapeutic bonds foster the woman's motivation to recover and desire to be a good parent. Programs should offer women the opportunity to build a relationship with a few key interventionists.

Many current drug treatment programs based on the therapeutic community model use a confrontational group process approach that is quite successful with men. Most treatment experts believe that chemically dependent pregnant women require specialized treatment models that include groups made up solely of these women in order to encourage contact and interaction, peer support, and focus on common problems.

6. Programs Should Be Culturally Competent

Program staff need to be responsive to the specific racial, ethnic, and cultural backgrounds of women using the service.

7. Residential Treatment and / or Drug-Free Housing Must Be Available

Treatment experts strongly recommend that patients be encouraged to leave their living environments where drugs may be readily available and commonly used. Options include residential treatment programs for those most severely chemically dependent, as well as drug-free housing for all others. Children must always be included in all residential options.

8. Programs Should Include Parent Education and Quality Child Care

Women want to be good parents. Often their natural inclinations are unsuccessful because their drug-exposed infants are difficult to parent. Sensitive parent education can help them understand their babies and care for them effectively. "Hands on" experiences in parenting should be part of any residential treatment program. The integration of infants and young children into residential treatment programs should be done in a manner that supports the mother-infant bond as well as allows mothers time and energy for recovery.

Quality infant care is especially important for drug-exposed infants. Special attention should be paid to the development of a bond between infants and their principal caregivers. When addicted mothers are in treatment or meetings or otherwise engaged, it is important for infants to be cared for in a manner that promotes trust and security.

B. Locating Treatment Programs

Services for substance-using women and their children are often fragmented. In attempting to locate treatment programs in a given city or State, contact the public health agency for that jurisdiction and investigate *both* the maternal and child section of the agency and the substance abuse treatment section. In other instances, the child welfare agency in the particular jurisdiction may have more access to information than the public health agency. States vary greatly in terms of how and where the services for substance-using women are coordinated. In any event, patience and persistence are key assets in trying to locate these services. Certain national nonprofit and Federal agencies can also provide assistance in locating services. For example, the Child Welfare League of America is planning to produce a document highlighting treatment programs for substance-using women and their children.

C. Sample Comprehensive Programs

Here is a sample of programs in each area of the country, giving the reader an understanding of the range of programs that now exists for this population. Differences in the treatment approaches, philosophy, and sponsoring agencies are reflected in each description. In residential treatment programs, specifics such as the length of stay for treatment and the number and age of the children who can accompany the mother to the facility vary greatly.²

WEST COAST

CALIFORNIA

California has numerous comprehensive programs for substance-using women and their children. The following three are especially noteworthy.

SOLID FOUNDATION

P.O. Box 19183
Oakland, CA 94619
415-482-3217

The Solid Foundation operates two residential programs for women: Mandela House and Keeler House, serving five or six women. The program provides comprehensive treatment, including prenatal and perinatal care and education in child development (with an emphasis on the special needs of drug-exposed children), transportation, job training, GED preparation, nutrition information, religious counseling, personal grooming, group and individual counseling, and a therapeutic nursery. Women live in the house with their infants for 12 to 18 months. Mothers are involved in the design, policies, and implementation of the program and often volunteer for service after graduation. The program has received many awards.

CHEMICAL ADDICTIONS RECOVERY EFFORTS (CARE) CLINIC

Children's Hospital
5208 Claremont Avenue
Oakland, CA 94609
415-652-3783

CARE is an outpatient treatment program for up to 65 chemically dependent mothers and their drug-exposed infants, age 0 to 3 years, offering services both in the home and onsite. The focus is to help mothers maintain custody of their children, help mothers remain drug free, and help the children developmentally. Services include: comprehensive medical and psychosocial services, weekly group sessions, recovery support groups,

weekly staff home visits, parent education, therapeutic developmental nursery for children with developmental delays, support in obtaining transportation, housing, child care, and material items.

PROTOTYPES WOMEN'S CENTER

845 East Arrow Highway
Pomona, CA. 91767
714-624-1233

PROTOTYPES provides a wide range of services to substance-using women and their children and has both a long-term residential treatment program and an outpatient program. The residential program serves 55 women and up to 30 children for a period of 9 to 18 months. The program has four treatment phases: orientation, stabilization, reparenting, and community re-entry, with the women assuming increasing responsibility in each phase. Core activities of the program include: chemical dependency education, individual and group counseling, women's health issues group, family treatment, household responsibilities, vocational training, aftercare planning (including a "buddy" who assists in seeking Employment and gaining independence), recreational activities, and participation in 12-step groups. Specialized groups include: pregnancy, grief and loss, communication skills, relapse prevention, women's survivors, and parenting training. Children's activities include a therapeutic nursery, play groups, parent-child outings, and after-school tutoring for school-age children.

Appendix C - Urine toxicology Guidelines

1. **Specific urine toxicology techniques.** Drug toxicology tests are most commonly performed on urine, since most drugs and their breakdown products are excreted in the urine in higher concentrations than in the blood, and because urine toxicology tests are often inexpensive and quick. Alcohol toxicology tests are routinely performed on blood and breath as well as urine.
 - a. **Screening tests.** Overall, drug screening tests are rapid, technically simple, and economical. Generally, these tests are sensitive, meaning they can detect evidence of small amounts of drugs or drug metabolites. However, they are less specific and less reliable than confirmatory tests. In other words, drug screening tests are known to produce false-positive and false-negative test results.

Screening tests are typically batched, meaning that multiple urine samples are screened together. When a batch of multiple urine samples is found to be positive, the individual urine samples may be retested to identify the positive specimen. Once the urine sample has been identified as testing positive by a screening test, the specimen is retested with a more specific (and more expensive) confirmatory test. Two of the more common screening tests are thin-layer chromatography (TLC) and immunoassays.

 - TLC is a practical, economical, and sensitive method of detecting drugs in urine specimens. TLC is particularly useful because multiple specimens can be tested, and more than one drug can be determined for each application.

The test involves applying urine specimens onto a glass plate, which is sprayed with various reagents. The appearance and position of spots on the plate are used to identify the drug or drugs being sought. The certainty of the identification depends on the efficiency of the procedure, the ability of the technicians performing the assays, and the ability of those making the identification.

There are TLC screening tests for most drugs of abuse, including the opioids, the amphetamines, the barbiturates, cocaine, marijuana, glutethimide, and the phenothiazines.
 - Immunoassay techniques, such as the enzyme multiplied immunoassay technique (EMIT), are commonly used drug screening techniques in part because they are sensitive, quick, and require a small sample. Also, these tests can be easily automated and performed by a minimally trained individual not trained in toxicology. These tests utilize complex immunochemistry and the production of drug antibodies in an interaction with enzymic detectors to reflect the presence of various drugs subject to misuse.

In addition to EMIT, other examples of immunoassay techniques include radioimmunoassays and fluorescence polarization immunoassays. Most drugs of abuse are detectable by

drugs of abuse in urine.

The elimination of some drugs can be influenced by changes in urine pH, which can be altered by the ingestion of some acidic or basic substances. For example, PCP excretion can be somewhat accelerated by the ingestion of cranberry juice.

5. **Alternate methods of screening for substance abuse.** Other methods of screening for prenatal substance abuse are not readily available, and may not be acceptable in a court of law. These include testing of newborn meconium and radioimmunoassay of maternal hair. A recent large-scale prospective study of newborns shows that improved detection of exposed newborns can be achieved with meconium analysis.

Drug Durations

Drug Durations	
Drug	Duration
Amphetamines	48 hours
Alcohol	12 hours
Barbiturates	10-30 days
Valium	4-5 days
Cocaine	24-72 hours
Heroin	24 hours
Marijuana	3-30 days
Methaqualone	4-24 days
Phencyclidine	3-10 days
Methadone	3 days

Appendix D - Description of IDEA

Description of IDEA (Individuals with Disabilities Education Act)

The following is an article by Barbara J. Smith, Ph.D., provided by the Council for Exceptional Children. Since this article was written, both the title and number of the law has changed. Although the article's "PL 99-457" is now called "IDEA," the description is still valid.

Background

For over 20 years, the Federal government has been supporting research into the effectiveness of early intervention with handicapped and at-risk young children and their families. In addition to research studies, projects have been funded to develop model practices for effective early intervention.

These research and model development projects, along with programs such as Head Start, have proven that early intervention is effective. We know that if we provide support and services to children and families as early as the need is apparent, then: 1) the child's development will not be as delayed as it would be if left unattended until age 6 or older; 2) the stress for the family of having a handicapped child is lessened and they are able to function more productively; and, 3) because of these results, children and families are more able to contribute to their community - indeed, early intervention can prevent the need for many costly services later in life.

In recognition of the effectiveness and critical importance of early intervention, the United States Congress passed Public Law 99-457 in September, 1986.

Overview

P.L. 99-457, the Education of the Handicapped Act Amendments of 1986, includes provisions for handicapped children of all ages, as well as for personnel and other activities. However, the most dramatic provisions of this new law relate to handicapped and at-risk children between the ages of birth and six and their families. Indeed, the law states:

"The Congress finds that there is an urgent and substantial need:

1. to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay;
2. to reduce the educational costs to our society, including our nation's schools, by minimizing the need for special education and related services after (they) reach school age;
3. to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society; and,
4. to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps." Regarding young children and their families, P.L. 99-457 established two new Federal programs. One new program addresses 3- through 5-year-old handicapped children, and the other addresses handicapped and at-risk infants and toddlers from birth to age three.

The Preschool Grant Program

First, P.L. 99-457 creates a new mandate for State education agencies to serve all three, four, and five year-old handicapped children by 1990-1991. This new preschool mandate was achieved by lowering the P.L. 94-142 mandate to age three. P.L. 94-142, the Education for All Handicapped Children Act of 1975, created a "right to education" for handicapped children between ages six and eighteen. However, to encourage States to serve children below the ages of six, Congress created the Preschool Incentive Grant in 1975, which, instead of mandating, simply provided some incentive monies. Now this "right to education" is extended to children beginning at age three.

This new Preschool Grant Program changes the old Preschool Incentive Grant in several ways - it is, in fact, a mandate, rather than an incentive, and it provides more than three times the funding for 3-5 year-olds!

Who are the Eligible Children?

The Preschool Grant Program's purpose is to extend P.L. 94-142 rights to children from age three, including all definitions and requirements. Moreover, three, four and five year-olds are eligible for services under this new program if they are handicapped according to one or more of the P.L. 94-142 diagnostic categories: deaf, deaf-

blind, hard of hearing, mentally retarded, multi-handicapped, orthopedically impaired, other health impaired, seriously emotionally disturbed, specific learning disability, speech impaired, and visually handicapped.

However, Congress made an important distinction for the preschooler: the documentation and count of children required by the Federal government from the States does not have to be by diagnostic category for this age group. This allows States to serve 3-5 year-olds without labeling them.

P.L. 94-142 was changed a second way for this age group: parental instruction is an allowable cost, rather than only services delivered directly to the child. This was in recognition of the important role parents play in the lives of preschool-aged children. Finally, P.L. 99-457 preschool services differ from school-aged requirements under P.L. 94-142 in that variations in length of day, or service model (home-based, center-based, etc.) are encouraged. Also, local education agencies are encouraged to contract with appropriate existing non-public school community preschool programs to provide a range of services and service models such as the mainstreaming opportunities offered by Head Start.

What is Mandated?

P.L. 99-457 requires that States, through their State education agencies, participating under P.L. 94-142, ensure that they are providing a "free, appropriate, public education" to all handicapped children beginning at age three, by 1990-91. Currently, all States ensure that they are providing appropriate services, including individualized education programs (IEP), due process, least restricted environment, non-discriminatory testing, parent involvement, and support services to all handicapped children beginning at age six. About half the States currently serve three, four, and five year-olds.

Funding Level

The Preschool Grant Program has two channels of funds: a) one for reimbursing school districts for children served in the previous year (served children); and, b) one for advance payment for the number of additional children the State reports they *intend* to serve the following year (unserved children).

Served children will generate up to \$300 / child in fiscal year 1987; \$400 / child in fiscal year 1988; \$500 / child in fiscal year 1989; and \$1,000 / child thereafter. Unserved children generate up to \$3,800 / child until 1990, then all children generate up to \$1,000 / child.

If the State does not, in fact, serve all the unserved children they intended to serve and received advanced payment for, their next year's allocation will be adjusted downward. Similarly, if the State serves more unserved than intended, the following year's allocation is adjusted upward.

Failure to Comply

If a State does not ensure a free, appropriate, public education beginning at age three to all handicapped children by 1990-91, it will lose the following Federal funds:

- all Preschool Grant Funds;
- all P.L. 94-142 dollars that were generated by the 3-5 year-olds;
- and all grants and contracts related to preschool special education funded under the Education of the Handicapped Act discretionary programs.

Handicapped Infants and Toddlers Program

The second landmark early intervention program established by P.L. 99-457 is the Handicapped Infants and Toddlers Program. This section of the law creates a brand new Federal program for handicapped and at-risk children from birth to age three years and their families. The Congressional purpose of this program is to provide financial assistance to States to:

1. develop and implement a Statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services;
2. facilitate the coordination of early intervention resources from Federal, State, local, and private sources (including private insurers); and
3. enhance States' capacities to provide quality early intervention services.

While the infant and toddler program is voluntary for States - that is, they may elect to not participate - if a State does choose to participate, or apply for funding under this law, it must meet the requirements of the law. And, to be eligible for a grant in the fifth year, the State must assure that services are available to all eligible children.

Eligibility

The new Infant and Toddler Program is directed to the needs of children, birth to their third birthday, who need early intervention because they

1. are experiencing developmental delays in one or more of the following areas: cognitive, physical, language and speech, psychosocial, or self-help skills; or
2. have a physical or mental condition that has a high probability of resulting in delay (e.g., Down's Syndrome, cerebral palsy, etc.) or
3. at State discretion, are at risk medically or environmentally for substantial developmental delays if early intervention is not provided.

Secondly, the infant and toddler's family may receive services under this program that are needed to facilitate their capacity to assist in the development of their child.

States' Role

If a State applies for funds under this program, it must meet the following requirements:

The first two years:

1. the governor has established an Interagency Coordinating Council made up of parents, providers, State agency representatives, personnel trainers, State legislature representatives, and others;
2. the governor has designated a lead agency (which may be the Interagency Coordinating Council); and,
3. the State assures that the funds will be used to plan, develop and implement Statewide services.

Appendix E - Family Service Plan

Individualized Family Service Plan (IFSP)

Individualized Family Service Plan (IFSP)
Child's Name: Jane Doe
Birthdate:

Age

Developmental Levels:

<u>15-18</u> months	Fine Motor	<u>12-15</u> months	Gross Motor
<u>15-18</u> months	Cognitive	<u>18-21</u> months	Language
<u>12-15</u> months	Self-Help	<u>18-21</u> months	Social/emotional

Child Strengths and Needs:

Jane's developmental strengths are in her ability to communicate and interact with her mother, aunt, and brother and sister. Despite her many health problems, Jane's temperament is sunny, and her disposition makes it easy for her to get the adults around her involved with her.

Jane's physical health varies considerably as a result of her HIV infection and this affects her motor development, which is very uneven. Jane has persistent diarrhea and recurring ear infections. Jane is a fussy eater and sometimes throws food she doesn't like or want. She doesn't have many opportunities to play with or be around other young children, which would allow her to make the most of her good language and social skills.

Family Strengths and Needs:

Theresa is deeply committed to keeping her family together and to caring for Jane at home as long as she can. Theresa's periods of being sick with HIV make it hard for her, at times, to manage the demands of taking care

of Jane. She has a lot of help from Yvonne and Julie, both of whom are great sources of support and can be relied on to help out whenever they are needed. Yvonne goes grocery shopping for the family, helps Julie with her school work, takes Jane and Theresa to medical appointments, and has made a home for Roger with her family. Because Theresa relies so heavily on Yvonne and because Yvonne disapproves of Theresa's drug use so strongly, Theresa wants to enter a treatment program again.

Julie is devoted to her little sister and helps out with her every chance she gets. Julie says she wants to be a very important part of Jane's IFSP team.

Right now, mealtimes are not good times at the Doe's. Theresa is often too tired to cook dinner and then coax Jane to eat, but she worries about Jane not getting enough to eat and wants to see her grow stronger. Julie manages dinner whenever Theresa is too tired, but she isn't sure what she can make for dinner that Jane would like and want to eat. Theresa also wants some time alone during the day to rest when she isn't feeling strong, and she hopes Jane will have a chance to be around other young children. Theresa needs a stroller in order for her to be able to take Jane out of the house.

Outcomes:

1. Theresa wants to control her drug addiction in order to maintain her good relationship with her sister.
2. Theresa wants Jane to be in day care, so that Theresa has some time during the day and so that Jane can have a chance to play with children her own age.
3. Theresa and Julie want some help at mealtimes in order for Jane to learn how to eat more foods, be less fussy, and grow stronger.
4. Jane will have physical therapy in order to increase her body strength and mobility and make it possible for Theresa and Julie to take care of her at home.

Outcome: #1

Theresa wants to control her drug addiction in order to

maintain her good relationship with her sister.

Strategies/Activities:

1. Theresa, Dolores (the WIN service coordinator), and Betty (Theresa's hospital social worker) will discuss Theresa's options for a drug treatment program.
2. Theresa will choose the option she prefers and will call to refer herself within a week of the discussion.
3. If there is a waiting list, Betty will arrange for Theresa to have a priority admission because of her illness.
4. Theresa will complete the intake process for the treatment option she chooses and will go to treatment sessions as scheduled. Dolores or Betty will go with Theresa to her appointments whenever she asks.
5. Betty, Dolores, and Yvonne will help and support Theresa, encouraging her efforts. Theresa will tell Dolores and Betty when she feels like using drugs, and they will tell Theresa whenever they think she is using drugs.

Criteria/Timelines:

Theresa will determine if she is making progress overcoming her drug addiction. She suggested that she review her progress with Dolores every month.

Outcome: #2

Theresa wants Jane to be in day care so that Theresa has some time to rest during the day and so that Jane can have a chance to play with children her own age.

Strategies/Activities:

1. Dolores will investigate day care centers within walking distance of the Doe's house and will talk over the options with Theresa.
2. Theresa will make a choice from the options.
3. If the publicly funded day centers are not available or are inappropriate for Jane, Betty will arrange for Theresa to get financial assistance from the Department of Social Services or the hospital to pay the fees.
4. Dolores and Theresa will enroll Jane together as soon as possible. Yvonne will try to get a friend to loan Theresa a stroller. If this doesn't work out, Betty will ask social services to buy a stroller so that Jane can go to daycare.
5. Theresa will take Jane every morning to the center when she is well enough to take her. Julie will pick Jane up in the afternoon. Dolores will arrange for a home health aide or visiting nurse to help out during the day with Jane when either Jane or Theresa is not well

enough to manage alone.

6. When Theresa and Jane are both well, Theresa will take Jane in her stroller to the park down the street once a week.

Criteria/Timelines

The timelines are as listed above in the activities. Theresa will decide if she is satisfied with the way things are going and if her need has been met as specified in the outcome.

Outcome: #3

Theresa and Julie want some help at mealtimes in order for Jane to learn how to eat more foods, be less fussy, and grow stronger.

Strategies/Activities:

1. Dolores will arrange for a home nutritionist or visiting nurse to come to the Doe's five evenings a week, beginning in two weeks.
2. The home visitor will help Theresa and Julie make a list of several finger foods that are good for Jane and that she likes and is able to eat.
3. The home visitor will show Julie how to make several easy to prepare dishes that Jane likes and is able to eat.
4. John Bennett, the WIN occupational therapist, and Dolores will do a feeding evaluation of Jane next week, before the home visitor comes to determine if Jane has any special feeding problems and will develop a plan with Theresa, which would become a part of this IFSP, to remediate the problem if one exists. The evaluation will be done at home at a regular mealtime.
5. Yvonne will continue to do the grocery shopping for the Doe's, now using a list that Julie has made for her.

Criteria/Timelines:

The timelines are as listed above in the activities. Theresa will decide if she is satisfied with the way things are going and if her need has been met as specified in the outcome.

Outcome: #4

Jane will have physical therapy in order to increase her body strength and mobility and make it possible for

Theresa and Julie to take care of her at home.

Strategies/Activities:

1. Charlene Cangelosi, the hospital physical therapist will visit Theresa and Jane at home once a week to monitor Jane's motor development for signs of loss of previously attained skills.
2. Charlene will work with Jane on her balance and righting reactions. She will show Julie and Theresa how to play with Jane in a way that gives her practice in these activities.
3. When Julie plays with Jane, she will play in the way that Charlene is teaching her.
4. Dolores will come to one of Charlene's sessions every month to learn how Jane is doing.

Criteria/Timelines:

Jane's therapy will begin next week. Charlene will use clinical observation to judge Jane's progress or Jane's maintenance of previous motor skills, and will do a formal evaluation jointly with Dolores every three months to monitor Jane's motor development.

Notes on the IFSP Process:

Betty Allain, Theresa's hospital social worker, referred Theresa and Jane to Project WIN. The WIN assessment staff planned a transdisciplinary arena assessment with Theresa, Yvonne, and Julie. Betty became part of the team for the assessment.

Following the assessment, Theresa decided to enroll in Project WIN with Jane. Betty is part of Theresa's IFSP team, along with the occupational and physical therapists from the project. Yvonne and Julie are on the team, and Dolores Doiren will work with Theresa as her service coordinator.

Because Theresa and Jane have HIV, they may need the services of many agencies other than the hospital and Project WIN. New members will be added to this transagency IFSP team by Theresa, or with Theresa's consent as the need arises.

Theresa was very clear about the kinds of support she needed and plans to tell Dolores any time she needs or wants a change in the IFSP for Jane, Julie, Roger, or herself. Because Yvonne may need to take over for Theresa at any time should she become too ill to care for her family, Theresa has asked that Yvonne be a full member of the team and have access to all the records relating to Jane and the Doe's IFSP.

Appendix F - Medical Glossary

Abruptio placentae

Premature detachment of the placenta from the wall of the uterus.

Alkalosis

Abnormally increased pH from respiratory or metabolic causes.

Antepartum

before childbirth.

Cardiac arrhythmias

Alterations of the heartbeat.

Cavitation

Formation of space in an organ or tissue.

Causation

Causal role.

Cerebral infarctions

Dead or diseased areas of the brain.

Chlamydia

A microorganism of the genus *chlamydia*.

Decreased habituation

Decreased responsiveness after a repeated exposure to a stimulus.

Echocardiography

Noninvasive diagnostic procedure for the heart involving high frequency sound waves.

Echoencephalographic

Use of ultrasound in measuring/examining the internal structures of the skull.

Encephalopathic syndrome

Condition of brain pathology.

Feeding intolerance

Inability to effectively suck, swallow or retain feedings.

Genitourinary tract

System of organs related to reproduction and the production and excretion of urine.

Hemorrhagic ischemic lesions

Caused by bleeding or reduced blood flow.

Hypermetabolic

Excessively increased metabolism.

Hyperpnea

Abnormally rapid or deep breathing.

Hyperpyrexia

Exceptionally high fever.

Hyperreflexia

Overactivity of physiological reflexes.

Hyperthyroid state

Overactive thyroid gland, causing a state of increased metabolism.

Hypertonia

Excessive tone or tension of a muscle.

Hypoxia

Too little oxygen reaching the body tissues.

Hypoxemia

Deficient oxygenation of the blood.

Intrapartum

During childbirth.

Intraventricular hemorrhage

Bleeding within a ventricle of the brain.

Ischemia

Localized tissue anemia or narrowing of arteries by spasm or disease.

Ischemic injury

Local injury caused by impaired blood flow.

Labile state

Frequently changing.

Meconium aspiration

Fetus breathing or sucking in a mass of meconium, which is usually discharged shortly after birth.

Necrotizing enterocolitis

Inflammation of large and small intestines.

Neurotoxicity

Toxicity to the nerves or nervous tissue.

Philtrum

The vertical groove on the median line of the upper lip.

Respiratory alkalosis

Alkalosis caused by excessive elimination of carbon dioxide due to a respiratory abnormality, such as hyperventilation.

Sepsis

A toxic condition resulting from spread of bacteria or their products from an infection.

Tachycardia

Relatively rapid heart action.

Tachypnea

Increased rate of respiration.

Thrombocytosis

Abnormal increase in the number of blood platelets.

Vascular

Affecting tube(s) that convey a body fluid, such as blood.

Vasoconstriction

Narrowing of blood vessels.

Appendix G - Cost Factors

Cost Factors in the Diagnosis, Assessment, and Treatment of Drug-Exposed Infants

Background

Determining the cost of providing treatment to drug-exposed infants is perhaps as complicated as the treatment itself. With an infinite variety of clinical, financial, and data collection issues involved, it would be futile to attempt to attach monetary values to the many services, procedures, and tests necessary to provide care to this ever-increasing segment of the population. Prior attempts by various researchers to estimate costs, both on the national and patient levels, are only rough estimates. Consequently, the following discussion focuses on the issues involved in making cost estimates, mainly by recognizing that provider charges, or pricing, bear a direct relationship to cost.

Specifically, the most intensive component of the cost of treatment is the inpatient setting. It is this treatment phase for drug-exposed infants that is emphasized here. The purpose of this information is to provide guidance to State alcohol and drug abuse directors, treatment program directors, facility financial personnel, and neonatal intensive care unit (NICU) department chiefs for developing procedures dealing with pricing, cost finding, and budgeting. Included is the following information:

- An overview of factors influencing provider pricing;
- Strategies in evaluating provider charges and costs for the treatment of drug-exposed infants;

- A listing of the most frequent services, procedures, and tests utilized in providing neonatal treatment to drug-exposed infants; and
- Sample ranges of charges obtained from hospitals that provide Level II and III NICU treatment for drug-exposed infants.

An in-depth analysis of the medical management of the drug-exposed infant, as prescribed by the consensus panel, has resulted in a breakdown of treatment into three areas:

- Evaluation and management services
- Clinical procedures
- Pathology and laboratory tests.

These areas of treatment are further delineated into individual services, procedures, and tests as defined by the American Medical Association's Current Procedural Terminology (CPT). For each item, CPT-4 codes are supplied to assist with planning for the utilization, frequency, and accurate billing of treatment. Due to changes and updates in CPT coding from 1992 to 1993, both years' CPT-4 codes are provided.

Because of dynamic changes in treatment for drug-exposed infants, and the enormity of the costs of care - both immediate and long-term - a tremendous burden is carried by provider facilities to manage costs and pricing. The rapid growth in the numbers of drug-exposed infants, coupled with the current uncertainty of health care reform, will require difficult decision-making by providers, third-party payors, and Federal and State governments. Ultimately, success in treating drug-exposed infants will be determined by these sectors of the health care industry.

Factors Influencing Provider Pricing

When examining the various services, procedures, and tests in the TIP from a pricing perspective, it is evident that a wide variety of factors influence provider charges. Understanding these factors is crucial in attempting to identify costs, or to evaluate pricing for a particular treatment program for drug-exposed infants.

Several major factors influence provider pricing:

Clinical Intensity - Pricing is influenced by the type of patient (severity), the type of NICU (such as, Level II or III), and the patient's diagnosis and prognosis.

Volume of Services - Hospitals develop pricing for specific units or departments with an assumption about the volume of services that each department will generate. Accordingly, departments that project low utilization often have high average charges. Conversely, departments with longer lengths of stay and projections of higher volumes may have low average charges.

Charge Development Methodologies - Many hospitals use charge development methodologies that are designed to achieve a wide variety of facility-specific financial objectives. For example, facilities may want to subsidize losses in one department with profits from another, or subsidize bad debt and charity care with revenues from other payors. Competition within the hospital market, based on price or the degree of managed care penetration, can also influence prices. Additionally, a third-party payor mix will also impact pricing of provider services.

Input Costs - Providers have wide differences in the level of their input costs which, in turn, affect their prices. The costs of labor and supplies can be substantially different, even among hospitals that are in the same area.

Organizational Structure - Many hospital providers have developed into complex entities that consist of multiple related facilities integrated into a network. Accordingly, charges may be influenced by multiple market areas or entities. Specific charges may include an administrative or a technical fee. Additionally, the frequency of charges from a variety of provider entities is to be considered. Moreover, some organizations use an all-

inclusive rate concept that may cause room rates to be artificially high when compared to an organization that has an "unbundled" fee structure.

Cost Data - There is a wide variation in the quality of hospital cost information that supports price setting. Some providers have sophisticated cost finding and charge development systems, while others have very basic systems. Additionally, there are a wide variety of methodologies available within the more complex systems.

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[Exhibits]

Exhibit 1: Newborn Maturity Rating and Classification & Classification of Newborns Based on Maturity and Intrauterine Growth

Exhibit 1 of TIP 5: Improving Treatment for Drug-Exposed Infants is not available electronically. A copy of the entire TIP containing Exhibit 1 can be ordered from the National Clearinghouse of Drug and Alcohol Information (NCADI). The order number for TIP 5: Improving Treatment for Drug-Exposed Infants is BKD110. It is free and can be ordered from NCADI's electronic catalog at <http://ncadi.samhsa.gov/> or by calling 1-800-729-6686.

Exhibit 2: Neonatal Abstinence Score

Exhibit 2 Neonatal Abstinence Score					
SYSTEM	SIGNS AND SYMPTOMS	SCORE	AM	PM	COMMENTS
CENTRAL	Excessive	2	<input type="checkbox"/>	<input type="checkbox"/>	

DISTURBANCES	Poor Feeding	2																		
	Regurgitation	2																		
	Projectile Vomiting	3																		
	Loose Stools	2																		
	Water Stools	2																		
TOTAL SCORE																				
INITIALS OF SCORER																				
<p>Evaluator should place a check next to each sign or symptom observed at various time intervals, then add scores for total score.</p>																				

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