

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, re-parenting, 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

immunoassays, including the opioids, the amphetamines, the barbiturates, the cannabinoids, cocaine, and PCP.

- b. **Confirmatory tests.** The basic principle of confirming a positive drug test is to retest the same urine sample with a different type of test. It is standard to first test body fluids with sensitive but less specific tests, and to confirm positive test results by retesting with sensitive and highly specific tests. Confirmatory tests generally have few false positive results.
Gas chromatography / mass spectrometry (GC / MS) is the procedure generally accepted by the scientific community for the confirmed identification of drugs of abuse. GC / MS also allows for quantitative analysis. Most drugs of abuse can be confirmed with GC / MS.

2. **Forensic drug testing.** Since the word *forensic* indicates a relation to law or legal issues, forensic drug testing describes drug testing processes that meet legal standards, and which may be scrutinized in court. Forensic drug testing involves accepted standards for urine collection and storage, chain of custody, and laboratory standards.

On April 11, 1988, the "Mandatory Guidelines for Federal Workplace Drug Testing Programs" were published in the *Federal Register*. This Federal effort described scientific and technical requirements for forensic urine drug tests and procedures. It also described procedures for identifying, evaluating, and certifying laboratories to perform forensic urine drug testing for Federal Agency Drug-Free Workplace Programs.

While these standards were developed for workplace drug testing, they are equally applicable to forensic urine drug testing regarding drug-exposed infants.

- a. Laboratories that have received certification have been assessed and verified with respect to quality control. Laboratories are assessed with respect to adequacy of laboratory facilities, the expertise and experience of laboratory personnel, the excellence of the laboratory's quality control program, performance of the laboratory on proficiency tests, and compliance with standards as reflected in the laboratory inspection. A list of certified laboratories is published monthly in the *Federal Register*.
 - b. The guidelines specify that the initial or screening test shall be an immunoassay that meets the requirement of the Food and Drug Administration for commercial distribution. Also, the guidelines specify that all specimens identified as positive on the screening test shall be confirmed using GC / MS.
It should be mentioned that not all laboratories are certified. Further, not all laboratories use GC / MS for confirmation of positive screenings. Thus, addiction treatment professionals should directly inquire about certification, and whether the laboratory does a GC / MS confirmation. In particular, addiction treatment professionals should ask the laboratory what specific tests are being used for screening and confirmation.
3. **Factors contributing to false-positive, false-negative, and inconclusive results.** The appropriate collection, handling, and testing of urine specimens is critical to avoid false-positive, false-negative, and inconclusive test results.
 - a. *Specimen collection.* The acceptable standard for collecting urine specimens is observed urine collection, to avoid deceptive switching or purposeful contamination. Contamination of specimen container, preparing the surfaces through which test materials are to be collected, and cleaning the skin with isopropyl alcohol may cause false-positive results.
 - b. *Specimen handling.* Several errors may cause inconclusive or misinterpreted test results. Such errors include mislabeling, specimen confusion, misidentification of the subject, and breaks in the chain of custody. Contamination of equipment, failure to clean glassware, and operator error may result in test result error.
 - c. *Other factors.* Errors may occur during any type of scientific measurement process, including drug testing. Human mistakes such as test equipment operator error may cause test error. Since many drug tests rely upon technician interpretation, human error can occur during this last stage. Diluted urine can result in false-negative or inconclusive test results. Also, various drug tests will identify the presence of over-the-counter (OTC) drugs, prescribed medications, and some foods that are chemically related to drugs of abuse. Historic examples include the amphetamine-related OTC drugs phenylpropanolamine and ephedrine registering an amphetamine test as positive, as well as foods that contain poppy seeds registering an opioid test as positive. Many drug tests are routinely modified to reduce cross-reactivity and to increase drug specificity.
 4. **Drug detection times in urine.** The duration of detection times for all drugs depend to a great extent on the volume, dose, and duration of drug use. For example, marijuana is commonly detected three days following inhalation of a single joint, but can be detected as much as thirty days following cessation of chronic, high-dose use. Elimination times may differ between neonates and adults, but there is a paucity of information on elimination times in neonates. While the elimination rates of drugs are variable, the following table displays an approximate guideline of duration for detecting various

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:			
<p>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.</p> <p>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.</p>			
Family Strengths and Needs:			
<p>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</p>			

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"/>	

NERVOUS SYSTEM DISTURBANCES	High Pitched (other) Cry Continuous High Pitched (other) Cry	3																	
	Sleeps < 1 hour after feeding Sleeps < 2 hours after feeding Sleeps < 3 hours after feeding	3 2 1																	
	Hyperactive Moro reflex Markedly Hyperactive Moro reflex	2 3																	
	Mild Tremors Undisturbed Moderate-Severe Tremors Undisturbed	3 4																	
	Increased Muscle Tone	2																	
	Excoriation (specific areas)	1																	
	Myoclonic Jerks	3																	

	Generalized Convulsions	5																	
METABOLIC/ VASCOMOTOR/ RESPIRATORY DISTURBANCES	Sweating	1																	
	Fever < 101 (99-100.8F/37.2-38.2C) Fevers > 101 (38.4C and higher)	1 2																	
	Frequent Yawning (>3-4 times/interval)	1																	
	Mottling	1																	
	Nasal Stuffiness	1																	
	Sneezing (>304 times/interval)	1																	
	Nasal Flaring	2																	
	Respiratory Rate > 60/min. Respiratory Rate > 60/min with retractions	1 2																	
GASTRO- INTESTINAL	Excessive Sucking	1																	

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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