Abandoned Infants Assistance Programs:
Providing Innovative Responses on Behalf of Infants and Young Children

Family Welfare Research Group
School of Social Welfare
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EXECUTIVE SUMMARY

Introduction

Abandoned infants were children identified as "boarding" in hospitals in the late 1980s due to complications of prenatal drug or HIV exposure. Congress endeavored to provide protection and permanency for these infants in 1988 with the Abandoned Infants Assistance (AIA) Act (P.L. 100-505). In the law, Congress defined abandoned infants as "infants and young children who are medically cleared for discharge from acute care hospital settings but who remain hospitalized because of a lack of appropriate out-of-hospital placement alternatives."

The Act provided for the development of model service demonstration programs for infants and young children perinatally exposed to drugs and/or HIV with the purpose of preventing abandonment; providing the necessary services for these children and their families to remain together or to obtain appropriate foster care; recruiting, training, and retaining foster families and social service professionals to work with this population; and providing residential and respite care programs.

Congress reauthorized funding for the AIA programs with the Abandoned Infants Assistance Act Amendments of 1991 (P.L. 102-236). The new legislation expanded the scope of the programs to include the institution of comprehensive service sites, provision of services to all the caregivers of these children, and the establishment of a National AIA Resource Center to provide training and technical assistance to the demonstration projects.

At the time of this report, 32 comprehensive demonstration service programs, located in 18 States, are funded under the AIA legislation. This report incorporates 1992 data from 21 of the 24 service projects and 1994 data from 31 of the 32 projects, describes the effective service strategies of AIA programs, and illustrates the innovative practices resulting in reduced medical and child welfare costs.

AIA Clients - Families at Risk

Nearly 17,000 children, parents, and caregivers had contact with AIA programs in the first four years of AIA funded services (1990-1994). Over five thousand (5,352) infants, 5,621 biological mothers, and 2,881 siblings received services, reflecting the fact that these agencies are serving family members beyond the target infant. Relatively fewer (858) biological fathers and just over 1,000 other adults (including foster parents, adoptive parents, relative caregivers) were served by the AIA programs. For the remaining number of contacts, no services were provided.

Data were collected on the demographic and risk characteristics of the biological mothers and "target" infants and children served and on some of the service outcomes of AIA programs.
The predominant ethnic or racial group of biological mothers served were African-American (55 percent). The mean age of the mothers was 28.6 years. Sixty-three percent of the target infants were African-American. Although most children began receiving services as newborns, children received considerable follow-up care. The average age of the target child at the time of program intake was 10.7 months.

Six percent of the mothers were homeless, six percent were living in residential substance abuse treatment facilities, and two percent were incarcerated at the time of program intake. Almost half (49 percent) were living with family or friends.

More than one-third (37 percent) of the mothers served by the AIA programs did not graduate from high school. Just under one-quarter (23 percent) either graduated from high school or completed their Graduate Equivalent Diploma (GED).

Over one-third (35 percent) of the mothers were receiving AFDC at the time of program intake. The mean annual income for the AIA families is $8,076, $804 below the $8,880 Federal poverty level for a family of two.

Of the mothers served who were reported as using substances (not confined to substance abuse during pregnancy), crack and other forms of cocaine were the most commonly used substance. 1994 data shows that 56 percent of the mothers were identified by programs as cocaine/crack users at the time of program intake. Alcohol was the second most commonly used substance (41 percent).

Half (50 percent) of the pregnant AIA clients received either late (second or third trimester) or no prenatal care. The majority (58 percent) exhibited evidence of drug or alcohol use during pregnancy. One-quarter of the target infants were born prematurely, and about the same number (26 percent) were identified as low birthweight -- an indicator of risk for infant mortality as well as for chronic respiratory and other problems. Of those infants tested, 44 percent were identified as substance-exposed at the time of delivery.

Mothers served by AIA programs were more than one hundred times more likely to be infected with the human immunodeficiency virus (HIV) than women of child-bearing age in the United States overall. Eighteen percent of the mothers for whom data were reported are known to be HIV positive. For those infants whose HIV status was known to the programs, nine percent were HIV positive at birth.

At the time of program intake or first assessment, 11 percent of the biological parents served by AIA programs were in early recovery from addiction while twice as many (23 percent) were in early recovery at termination or most recent assessment. While, at intake, 66 percent of the biological parents abusing substances were not in treatment, this was the case for only one-quarter at termination or most recent assessment.
At the time of program intake, half of the target infants/children were home with their biological parents or with other relatives, while 16 percent were hospitalized and 13 percent in the care of foster parents. At termination from AIA programs, only .2 percent of the target infants/children were hospitalized; the majority were home with their biological parents (51 percent), with relatives (13 percent), or in a foster care home (15 percent).

AIA Program Services

The AIA programs are diverse and operate out of hospitals, community-based child and family service agencies, and state and local child welfare agencies. While each program provides a package of services tailored to its specific circumstances, in the aggregate they provide the following services to their client families, either directly by AIA-funded staff or by referral to collaborating agencies:

- Case management;
- Infant developmental screening and intervention;
- Transportation assistance;
- Basic resource assistance (e.g. food, clothing, infant needs);
- Parenting education and support;
- Mental health counseling;
- Primary health care for women and children, including prenatal care; and
- Drug treatment.

All of the families (biological and caregiver) served by the AIA programs received case management, with the vast majority of those (87 percent) receiving the service directly from the AIA program. Infant/child development/education was the second most frequently received service by AIA families (72 percent). More than two-thirds of the clients served received transportation assistance (70 percent) and in-home services (67 percent). Over one-half of the AIA clients received food and/or clothing donations (63 percent), parenting education/support (55 percent), and primary medical care (51 percent). In addition, 31 percent of AIA clients received HIV screening/assessment and 21 percent received other HIV related services such as HIV education.

Overall, the trend in AIA program service delivery is toward the direct provision of supportive services such as case management, parenting education and support, and some concrete services (transportation, food, and clothing) and indirect provision of most medical care and drug treatment through referrals.

Innovative Services

The infants and families served by AIA programs are among the neediest clients in the health and human services systems, beset by chemical addiction, HIV/AIDS, poverty, homelessness or inadequate and unstable living arrangements. Infants exposed to drugs and/or HIV in utero often need specialized health care and therapeutic interventions to help them recover from
early physical and developmental traumas. Parents typically need assistance with housing and transportation, health care, drug and alcohol treatment, and parenting and supportive therapeutic services to help them address the day-to-day challenges of their lives.

The challenge for the AIA programs is substantial. The programs must mobilize and coordinate a variety of services from fragmented health and human services systems, and provide those services to a client population which is wary of the professional community and has little initial use for such interventions.

Based on interviews with AIA program directors and staff and a review of program materials, strategies which constitute the core of innovative AIA services with drug-exposed and HIV/AIDS-affected families have been identified. These include:

- **Interagency collaboration** -- to coordinate service development and funding between multiple agencies serving the same population;

- **Intervention teams** -- which bring together professionals from a variety of disciplines in the planning and delivery of services;

- **Peer services** -- which use paraprofessionals from the community to provide outreach, education, and supportive services;

- **Home-based services** -- which provide educational, supportive, and therapeutic services in the home of the client;

- **Culturally appropriate and women-focused services** -- which adapt educational and therapeutic interventions to reflect cultural and ethnic differences and the special needs of women, particularly those with young children;

- **Coordinated medical and social services case management** -- which reduce medically unnecessary hospital days and expedite discharges to the most family like settings; and

- **Legal, policy, and program development** -- to promote permanency for HIV-affected children and to help keep children orphaned by AIDS from entering the child welfare system when other resources can be identified.

Each of these innovations is briefly described in this report. Examples of program activities and cases studies illuminate the significance of these developments.

**AIA Program and Case Studies**

Three AIA programs are highlighted in this report: Project Prevent in Atlanta, Georgia; Hudson Cradle in Jersey City, New Jersey; and SPARK in Philadelphia, Pennsylvania. Each case study describes the AIA program, provides a client example demonstrating innovative service delivery strategies used by the program, and details client and cost outcome data.
These AIA program and case studies describe how their respective intervention methods are effective in assisting infants and families with chemical addictions and/or HIV/AIDS. AIA programs have been successful in: identifying potential boarder babies early on and expediting their release from the hospital; providing transitional residences for boarder babies and medically fragile infants; assisting biological mothers with receiving prenatal care, services for HIV/AIDS and drug treatment services; and working to achieve permanency for babies and, whenever optimal, care of the children by their biological parents.

Several AIA programs report substantial cost savings by avoiding prolonged and unnecessary boarding of infants at hospitals and by assisting pregnant drug addicted women to achieve healthy, drug-free births which decrease the medical care needs of their infants. In addition to decreasing hospital and medical costs, AIA programs endeavor to lower child welfare expenditures by working with parents and other caregivers around family reunification, by reducing the number of children unnecessarily falling into state custody and foster care, and by providing parents with skills and services so that they can become more self sufficient.

**Conclusions and Future Directions**

AIA programs provide a source of innovation for service providers from nearly all disciplines who work with drug and HIV-affected families. These programs continue to broaden the array of services they provide directly and by referral. New initiatives have arisen to enhance the provision of permanency for HIV-affected children and to ensure that children orphaned by AIDS do not unnecessarily enter foster care.

Provision of coordinated social and health service efforts to reduce medically unnecessary hospital days continues to be a fundamental goal of AIA programs. The size of the population of infants at risk of becoming boarder babies continues to be substantial. The interventions include system changes that result in expedited decision making and discharges, the development of new programs to serve children outside of hospitals, and assiduous case work. New approaches to overcoming newly identified barriers to prompt and appropriate decision making and services are still evolving.

Given the steady growth of drug and HIV-affected families, the ongoing development of AIA programs toward greater comprehensiveness, and the innovation that these projects can provide for other social and health service providers, the continued support of AIA programs is warranted.
I. INTRODUCTION

Background

Abandoned infants were children identified as "boarding" in hospitals in the late 1980s due to complications of prenatal drug or HIV exposure. Congress endeavored to provide protection and permanency for these infants in 1988 with the Abandoned Infants Assistance (AIA) Act (P.L. 100-505). In the law, Congress defined abandoned infants as "infants and young children who are medically cleared for discharge from acute care hospital settings but who remain hospitalized because of a lack of appropriate out-of-hospital placement alternatives" (section 103).\footnote{Every year across this country, a few infants are deserted by their parents - left unattended without any notice or adult supervision. Descriptive headlines read: "Mother Leaves Her Baby", "Baby Left at Penn Station", "Baby Found in Trash Compactor", "Second Baby in Two Days is Abandoned". These infants typically start life in the child welfare system as abused or neglected children, and are eventually identified and cared for by relatives or foster parents. Although no statistics are kept on the numbers of such "throwaway" babies, we believe these incidents occur relatively infrequently.} The Act provided for the development of model service demonstration programs for infants and young children perinatally exposed to drugs and/or HIV with the purpose of preventing abandonment; providing the necessary services for these children and their families to remain together or to obtain appropriate foster care; recruiting, training, and retaining foster families and social service professionals to work with this population; and providing residential and respite care programs. Congress reauthorized funding for the AIA programs with the Abandoned Infants Assistance Act Amendments of 1991 (P.L. 102-236). The new legislation expanded the scope of the programs to include the institution of comprehensive service sites, provision of services to all the caregivers of these children, and the establishment of a National AIA Resource Center to provide training and technical assistance to the demonstration

In 1993, James Bell Associates conducted a nationwide study of 573 hospitals to estimate the numbers of abandoned infants and boarder babies. Based upon the legislation, their report distinguishes boarder babies from abandoned infants, defining them respectively as infants under twelve months of age who remain in the hospital beyond the date of medical discharge and infants under twelve months of age who are unlikely to leave the hospital in the custody of their biological parents upon discharge. The study estimated a national prevalence of 10,000 boarder babies and 12,000 abandoned infants.

Characteristics of Abandoned Infants and their Families

In order to understand the phenomenon of infant abandonment, one must understand the magnitude of the issues confronting mothers of these children. The women have very few resources and are often struggling with: (1) poverty; (2) homelessness; (3) physically, sexually, and emotionally abusive relationships; (4) HIV infection; (5) mental illness; and (6) drug addiction. Researchers have reported that the average age of these mothers is 27 (Abedin, et al, 1993; Ramler, et al, 1994); the average number of pregnancies is four; 64 percent of the mothers receive no prenatal care; and 27 percent are incarcerated during their pregnancies (Abedin, et al, 1993). Many mothers: (1) have other children in out-of-home

2In FY 1990 - FY 1992, some funds were transferred to the Maternal and Child Health Bureau (MCHB) to assist them in expanding their pediatric AIDS programs to provide a broader range of services to families impacted by substance abuse and AIDS.
placements; (2) have very little, if any, social supports; (3) delivered their newborns alone; and (4) are homeless (Marcenko, et al, 1992). Additionally, 45 percent of the mothers have not graduated from high school, 62 percent receive income assistance, and 80 percent use multiple substances.

These mothers are also more likely than women of child-bearing age in the United States to be infected with HIV (Ramler, et al, 1994). AIDS is now the fourth leading cause of death for women aged 25-44 (Levine and Stein, 1994), and 92 percent of the 2,617 children under age 13 with AIDS, as of December 1994, were infected prenatally (Division of HIV/AIDS Prevention, 1994). By the year 2000, researchers estimate that as many as 125,000 children and adolescents will be orphaned because of AIDS. Although the large majority of these children are not HIV-infected, they are at high risk for behavioral and developmental difficulties (Levine and Stein, 1994). At least 80 percent of these children come from poor communities of color and single parent households, having to contend with violence, drug abuse, chaos, and homelessness in addition to HIV.

HIV infection is relatively prevalent in abandoned infants. As many as eight percent of infants abandoned in hospitals are reported to be HIV infected (Abedin et al, 1992; James Bell Associates, 1993), as compared with approximately 0.04 percent of all infants in the United States who are HIV infected each year (National Center for Health Statistics, 1994; National Institute of Allergy and Infectious Disease, 1994). Due to inconsistent testing and confidentiality laws, this number may underestimate the magnitude of the problem.
Substance abuse also has been indicated as a significant factor in cases of infant abandonment in hospitals. Approximately 80 percent of these babies are prenatally exposed to illicit drugs (Abedin et al., 1992; James Bell Associates, 1993; Marcenko et al., 1992), as compared with between five and approximately 11 percent of all babies born in the United States (National Association for Perinatal Addiction Research and Education, 1989; NIDA, 1994, Vega, et al., 1993). About one-third of the illicit drug users also smoked tobacco and/or drank alcohol during pregnancy (NIDA, 1994).

Most effects of drug exposure on growth and behavior now appear to be relatively modest and transitory (Zuckerman, 1993). Still, in a minority of cases, drug exposure does cause serious problems, and even disastrous ends, to pregnancy (Robins and Mills, 1993). As a result of prenatal drug and/or HIV exposure, abandoned infants have been reported to be susceptible to such health concerns as premature birth, low birthweight, fetal growth retardation, brain hemorrhages, strokes, neural tube defects, malformations of the heart, immature respiratory systems, reduced head size, mental retardation, tremors, seizures, hypersensitivity, and failure to thrive (Abedin et al., 1992; James Bell Associates, 1993; Melnick, 1992).

Financial and Social Implications

The abandoned infant crisis places new demands on overwhelmed medical care and child welfare systems. The Child Welfare League of America (1992) cites a figure of $805 per child in daily hospital boarding costs with average lengths of stay of 85 days (Abedin et al., 1993). James Bell Associates (1993) calculated the costs of care for abandoned infants to
range from $22.3 million to $125 million per year. This crisis not only affects the bottom lines of many hospitals, it also diminishes patient care, as abandoned infants displace infants in need of acute medical attention. This problem is particularly difficult for public hospitals that are unable to turn patients away that have been "shifted" from private hospitals, and most severely affects hospitals located in inner-city areas.

Additionally, although acute hospital care may cost up to 11 times as much as foster care, it does not provide an environment with adequate stimulation that growing infants need (Abedin et al, 1993). The postnatal environment is at least as important as the prenatal environment in determining outcomes in child development (Zuckerman, 1993). Appropriate early intervention services and stable home environments can help mitigate some of the damaging effects of prenatal drug and alcohol exposure (Abedin et al, 1993; Chasnoff, 1988; Melnick, 1992). A hospital setting's sterile shift care is not conducive to providing such services and fully addressing an infant's developmental needs.

Child welfare agencies are having to try harder than ever to locate and finance appropriate social services for infants abandoned in hospitals and AIDS orphans. According to the U.S. General Accounting Office (1990), 26 to 58 percent of drug-exposed children, as compared with only one to two percent of non-exposed children, were referred for foster care. In 1989, The American Public Welfare Association estimated that in Philadelphia over 70 percent of the new cases in children's protective services involved drug-exposed infants. One of the most

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3In a 1993 study conducted at Washington D.C.'s General Hospital, costs for one abandoned infant averaged $8400 per month versus $443-5754 per month for foster care (Abedin et al, 1993).
pressing issues facing parents dying of AIDS is planning care for their children. This is often complicated by denial, fear of disclosure to family and friends, unavailability of potential guardians, lack of professional legal and counseling services, and inflexible laws (Teare, 1994).

The continued need for services expressly designed for families with infants is evidenced by foster care demographics. Children aged zero to four are twice as likely as children aged five to 17 to enter foster care, with infants accounting for almost 25 percent of all foster care admissions in our largest states (Goerge, et al, 1994). Infants are no less likely than older children to re-enter the foster care system once reunification efforts have failed with nearly one-in-four young children eventually re-entering foster care (Barth, et al, 1995). With younger, more vulnerable children entering the child welfare system in increasing numbers, child welfare services must continue to adjust to meet the increased needs of this population (Barth, 1995).

The abandoned infant, perinatal substance abuse, and AIDS orphans crises are symptoms of the much larger social problems of poverty, urban decay, violence, and homelessness. For many parents, substance abuse, which in many cases may lead to exposure to HIV, is a way to escape the harsh realities of their daily lives. Many mothers feel unable to care for their infants and seek help through drug treatment programs (Marcenko, et al, 1992). Unfortunately, as few as 11 percent of pregnant women in need of drug treatment may actually receive services (Gustavsson, 1992) because many programs do not accept pregnant women
and/or women with children, and some women avoid treatment for fear that punitive action will be taken against them. Children orphaned by AIDS suffer not only the devastating loss of a parent, but also suffer from the stigma, secrecy, and denial that often accompany the disease (Levine, 1993). We can begin to address the underlying problems of infant abandonment, parental drug use, and AIDS orphans by increasing the availability of drug treatment programs, HIV prevention programs, affordable housing, family planning services, prenatal care, legal services, health/mental health services, case management services, and parent education classes in a humane and compassionate way.

The AIA Program

Programs funded under the AIA legislation are meeting some of these needs through collaborative, multidisciplinary, community-based initiatives. The AIA programs work with pregnant and parenting women, particularly those with a chemical dependency or HIV infection, who are at risk of abandoning their infants. Perinatal social services and specialized post-hospital care are reducing medically unnecessary stays. Family support is provided with the goal of preventing out-of-home placements. Support may include case management, assistance with resources, parenting education, the provision of maternal and pediatric care, and assistance with other basic needs. In those cases where out-of-home placement does occur, AIA programs recruit, train, and support relative caregivers, foster and adoptive parents, and help birth families work toward regaining custody of their children. They also assist children orphaned by AIDS to secure legal guardianship or adoption. Since enactment of the legislation, a total of 42 programs including five training projects, two resource
coordination projects, and a resource center have received support under the legislation. Thirty-one programs and the AIA Resource Center are currently operating.


Each service demonstration program was required to conduct an independent third party evaluation of its project. Information gathered from the projects found that data had been collected on 8,233 infants/children and 7,535 adults. This Report summarizes these data and describes effective strategies emerging from the experience of the AIA programs. These strategies are discussed in the three program illustrations highlighting effective programs that reduce hospital and child welfare costs.

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4 AIA program data come from a survey of the programs conducted by the National Abandoned Infants Assistance Resource Center and by third party evaluators.

5 It should be noted that no standard database has been established across sites (National Abandoned Infants Assistance Resource Center, 1992). One result of this situation is that the number of clients for whom data are reported varies per data item. The precise numbers of clients and programs, when not described in the text, are provided in footnotes.
II. AIA PROGRAM CLIENT POPULATION

Number of Families Contacted and Served

Nearly 17,000 children, parents, and caregivers had contact with the AIA programs during the first four years of operation (See Figure 1.). Of the nearly 17,000 contacted clients, 5,352 infants and 5,621 biological mothers received services. The programs spend considerable effort on outreach to biological mothers, however, 16 percent of the mothers contacted chose not to participate in the services offered by the AIA programs. This indicates some of the challenges faced by programs in engaging substance-abusing and HIV positive clients in a service-delivery system. Also receiving services were 2,881 siblings, indicating the family-centered nature of service providers.

In contrast, relatively fewer biological fathers had contact (889) with or were served (858) by the AIA programs. This could suggest that either fewer programs record these data or there is limited program involvement of biological fathers. Just over 1,000 other adults, including foster parents, adoptive parents, relative caregivers, and adults who were not primary caregivers, were served by the programs. Since some programs do not report demographic data and other information on clients until the case is closed and some programs reported

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6In addition to direct services, the service demonstration programs reported providing training or community education to close to 30,000 individuals, involved in service delivery to the target population, including child welfare workers, social workers, physicians and nurses. Training consisted of education about the AIA programs' services and referral procedures for the purposes of outreach as well as training on issues including perinatal substance abuse, HIV, child development, and the needs of medically fragile children.
difficulties in collecting information from all components of the program, the data reported in this section and others of this report are underestimates of the actual clients served and services provided.

Characteristics of Biological Mothers

Data were collected on the demographic and risk characteristics of the biological mothers served. These data included information on alcohol and drug use, source of income, provision of prenatal care, education, history of child abuse or neglect, HIV status, psychiatric history, housing, and family violence.
The majority (55 percent) of the biological mothers served were African-American; 22 percent were White, 13 percent were Hispanic, one percent were Asian/Pacific Islander, one percent were Native American, and the race/ethnicity of eight percent was unknown.7 (See Figure 2.) The mean age of the biological mothers served was 28.6 years old, with a range of 21 to 34 years.8

Figure 2

Race/Ethnicity of Biological Mothers Served by AIA Programs

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71992-20 programs reporting (n=2,082)
1994-29 programs reporting (n=3,776)
81992-17 programs reporting (n=1,340)
1994-26 programs reporting (n=3,573)
The biological mothers at the time of intake had many serious problems. Evidence of alcohol or drug use during pregnancy (as determined by a positive toxicology screen or a self report at the time of delivery or during the course of prenatal care) was found in more than half (58 percent) of the biological mothers. (See Table 1.) Evidence of no alcohol or drug use during pregnancy (a "clean" toxicology screen or self-report) was found in 12 percent of the women for whom data were reported, and 30 percent of the women's drug use during pregnancy was unknown.

**TABLE I**

*Biological Mother's Characteristic at Intake*

<table>
<thead>
<tr>
<th>Biological Mother's Characteristic at Intake 1992 and 1994 Data</th>
<th>Number of Clients</th>
<th>% With Characteristic</th>
<th>% Nation-Wide</th>
<th>% Without Characteristic</th>
<th>% Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than High School Graduation</td>
<td>5,362</td>
<td>37%</td>
<td>22%</td>
<td>32%</td>
<td>31%</td>
</tr>
<tr>
<td>AFDC Recipient</td>
<td>4,141</td>
<td>35%</td>
<td>7%</td>
<td>25%</td>
<td>40%</td>
</tr>
<tr>
<td>Late or No Prenatal Care</td>
<td>3,997</td>
<td>50%</td>
<td>22%</td>
<td>21%</td>
<td>29%</td>
</tr>
<tr>
<td>Alcohol/Drug Use During Pregnancy</td>
<td>4,774</td>
<td>58%</td>
<td>11%</td>
<td>12%</td>
<td>30%</td>
</tr>
<tr>
<td>HIV Positive</td>
<td>3,563</td>
<td>18%</td>
<td>0.15%</td>
<td>29%</td>
<td>53%</td>
</tr>
<tr>
<td>Psychiatric History</td>
<td>2,349</td>
<td>17%</td>
<td>NA</td>
<td>54%</td>
<td>29%</td>
</tr>
<tr>
<td>History of Child Removed due to Abuse/Neglect</td>
<td>3,351</td>
<td>41%</td>
<td>NA</td>
<td>44%</td>
<td>15%</td>
</tr>
<tr>
<td>Currently in Physically Abusive Relationship</td>
<td>2,663</td>
<td>17%</td>
<td>NA</td>
<td>44%</td>
<td>39%</td>
</tr>
<tr>
<td>History of Sexual Assault</td>
<td>2,223</td>
<td>26%</td>
<td>NA</td>
<td>33%</td>
<td>41%</td>
</tr>
</tbody>
</table>
Of the women served by the AJA programs who were reported as using substances (not confined to substance use during pregnancy), crack and other forms of cocaine were the most commonly used substance; 1994 data shows that 56 percent of the biological mothers were identified by programs as current cocaine/crack users. Alcohol was the second most commonly reported substance (41 percent), followed by tobacco (38 percent). One-quarter (25 percent) of the women served reported marijuana usage and 17 percent reported using other drugs including amphetamines, barbiturates, opiates including methadone, and PCP. Between 1990-92 and 1992-1994, opiate (e.g., heroin) and marijuana use increased the most. (See Figure 3.)

Figure 3

Biological Mother's Substance Use at Time of Intake into AJA Programs

*Substances refers to illicit drugs, drugs that may be legal but harmful to the fetus, and alcohol.

1992-16 programs reporting (n= 1,722). Not all programs collect data on specific drugs used by mothers.

1994-28 programs reporting (n= 3,229)
The mean annual income for the AIA client families was $8,076, $804 below the $8,880 Federal poverty level for a family of two. Over one-third (35 percent) of the biological mothers were receiving Aid to Families with Dependent Children (AFDC) at program intake. (See Table 1.) This is five times the general population receiving AFDC and/or Federal Supplemental Security Income (U.S. Bureau of the Census, 1992).

Half (50 percent) of the pregnant AIA clients received late or no prenatal care. (See Table 1.) Sixteen percent received no prenatal care at all, 12 percent began care in the third trimester, and 22 percent of the women began prenatal care in the second trimester. Data on the receipt of prenatal care were unknown for 29 percent. Only 21 percent obtained first trimester prenatal care. This is almost one-fourth the rate of women nationally (76 percent) and one-third the rate of African-American and Hispanic women nationwide (61 percent) who receive first trimester care (U.S. Department of Health and Human Services, 1991).

More than one-third (37 percent) of the biological mothers for whom data were reported did not graduate from high school. This is greater than the national rate (22 percent) of non-graduation from high school (U.S. Bureau of the Census, 1992). (See Table 1.) Just under one-quarter (23 percent) of the mothers for whom data were reported either graduated from high school or received their Graduate Equivalent Diploma (GED). Six percent received some college education, two percent completed two or four years of college and the educational attainment of 31 percent of the mothers was reported as unknown.

1992-8 programs reporting (n=1,340)
1994-10 programs reporting (n=3,573)
Forty-one percent of the mothers with children older than the target infant were reported to have had a child or children (other than the target infant) removed from their care due to child abuse or neglect prior to contact with an AIA program. (See Table 1.) No prior history of removal was reported for 44 percent of the biological mothers, and a history of child maltreatment was unknown for 15 percent of the biological mothers. Slightly over one-quarter (26 percent) of the mothers reported a history of sexual assault; 17 percent indicated that they were currently in a physically abusive relationship.

The women served by the AIA programs were over one hundred times more likely to be infected with HIV than women of child-bearing age in the United States overall. (See Table 1.) Eighteen percent of the women for whom data were reported are known to be HIV positive,¹² as compared to the national estimate of .15 percent of women of childbearing age estimated to be HIV positive (Quinn, et al, 1992).

Approximately 17 percent of the biological mothers were known either to have had a psychiatric diagnosis or to have been hospitalized for a psychiatric problem excluding drug and alcohol treatment. (See Table 1.) Slightly more than half (54 percent) of the women for whom data were reported have no known psychiatric history; information about psychiatric history was not available for 29 percent of the women. This statistic compares to 1989 U. S. Public Health data which show that 1.5 percent of all adult females, or almost 1.5 million adult females, are limited

¹²This may be an underestimate because of inconsistent voluntary testing/reporting and confidentiality issues. Over one-quarter (29 percent) of the biological mothers were reported as known to be HIV negative, and the HIV status for 53 percent was unknown.
by serious mental illness. These data are based on all females, not just females of child-bearing age (Mental Health U.S., 1992).

The living arrangements of the mothers illustrate the economic difficulties faced by the client families. Six percent of the mothers were homeless and two percent were incarcerated at the time of intake. Almost half (49 percent) of the women for whom data were reported were living with family or friends. Specifically, 25 percent of the women were living with their parents or other relatives, 18 percent were living with the child's father or another partner, and 5 percent were living with a non-relative. One-fifth of the women were not living with another adult.13 (See Figure 4.) A small percentage of the women (6 percent) were residing in residential substance abuse treatment facilities at program intake and the living arrangement of 16 percent of the women was unknown.

Figure 4

Living Arrangement of Biological Mothers Served by AIA Programs

131992-16 programs reporting (n= 1,379)
1994-23 programs reporting (n= 2,417)
Programs reporting on biological parents' length of time in substance abuse treatment or recovery at the time of program intake or first assessment and at the time of case termination or most recent assessment, show that 11 percent of the parents served by AIA programs were in early recovery from addiction while twice as many (23 percent) were in early recovery at termination or most recent assessment. While, at intake, 66 percent of the biological parents abusing substances were not in treatment, this was the case for only 25 percent at termination or most recent assessment. (See Figures 5 and 6.) At case termination or most recent assessment, seven percent of the women had been in recovery seven to twelve months, and five percent had been in recovery longer than one year. The recovery status of close to one quarter (23 percent) of the women was unknown.

*The term "early recovery" was not defined for the programs. In general, it means a period of initial abstinence, possibly three to six months, from the addictive substance.

**1994-10 programs reporting
Intake at First Assessment (n = 1,349)
Termination or Recent Assessment (n= 1,242)
Figure 5

Biological Parents' Length of Time in Substance Abuse Treatment or Recovery at Intake or at First Assessment

Unknown 6%
7 to 12 mos. 3%
1 to 6 mos. 8%
13 to 18 mos. 1%
19 mos. or more 2%
1 mo. or less 11%
1994 Data
Number Parents = 1,349
Number Programs = 10

Not a substance abuser 13%
Substance abuser - Not in treatment 66%

Figure 6

Biological Parents' Length of Time in Substance Abuse Treatment or Recovery at Termination or Recent Assessment

Unknown 23%
7 to 12 mos. 7%
1 to 6 mos. 12%
13 to 18 mos. 3%
19 mos. or more 2%
1 mo. or less 11%
1994 Data
Number Parents = 1,242
Number Programs = 10

Substance abuser - Not in treatment 25%
Not a substance abuser 17%
Characteristics of Infants Receiving Services

Although many families are served by AIA programs, a referral of an infant is typically the event that catalyzes services. AIA service providers were asked to report data on these "target" infants. Approximately six of ten (63 percent) target infants were African-American, 12 percent were Hispanic, 13 percent were White, two percent were Native American and the race of four percent was unknown.16 (See Figure 7.) The average age of the target child at the time of program intake was 10.7 months, ranging from birth to 52 months.17

Figure 7

Race/Ethnicity of Infants and Children Served by AIA Programs

1992 - 17 programs reporting (n=1,248)
1994 - 24 programs reporting (n=2,928)
1992 - 21 programs reporting (n=821)
1994 - 21 programs reporting (n=1,713)
The high level of maternal risk translated into developmental risk factors for target infants. (See Table 2.) Twenty-five percent of the infants were born prematurely (36 weeks gestational age or less) compared to just under ten percent nationally (U.S. Department of Health and Human Services, 1991). Only about half of the births were reported at normal birthweight. Low birthweight (1,500 to 2,499 grams), an indicator of risk for infant mortality as well as for chronic respiratory and other problems, was found among 26 percent of the AIA client births. Seven percent were born with very low birthweight (1499 grams or less). Nationally, 6.9 percent of all infants were born with low birthweight, and slightly more than one percent (1.2 percent) of all infants were born with very low birthweight. Nationally, for African-American infants, 12.7 percent were born with low birthweight and 2.7 percent with very low birthweight (U.S. Department of Health and Human Services, 1991). Based on positive toxicology reports, 44 percent of the target infants served by the AIA programs were born exposed to drugs and/or alcohol prior to birth. Thirty-nine percent were exposed to cocaine, two percent were exposed to opiates and one percent or less had a positive toxicology for barbiturates, marijuana, amphetamines or alcohol. Only one-quarter (25 percent) of the infants served were reported not exposed to substances in-utero. Drug-exposure status was unknown for 31 percent.

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*1992 - 15 programs reporting (n=1,305) 1994 - 19 programs reporting (n=2,378)*

*1992 - 14 programs reporting (n=1,265) 1994 - 19 programs reporting (n=2,378)*

*1992 - 11 programs reporting (n=909). Not all programs collect data on all drugs. 1994 - 17 programs reporting (n=2,404)*
TABLE 2

Target Infants with Characteristic at Birth

<table>
<thead>
<tr>
<th>Target Infants with Characteristics at Birth 1992 and 1994 Data</th>
<th>Number Clients</th>
<th>% With Characteristic</th>
<th>% Nation-wide</th>
<th>% Without Characteristic</th>
<th>% Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premature</td>
<td>3,683</td>
<td>25%</td>
<td>10%</td>
<td>53%</td>
<td>22%</td>
</tr>
<tr>
<td>Low Birth Weight</td>
<td>3,643</td>
<td>26%</td>
<td>7%</td>
<td>55%</td>
<td>19%</td>
</tr>
<tr>
<td>Drug Exposed</td>
<td>3,313</td>
<td>44%</td>
<td>11%</td>
<td>25%</td>
<td>31%</td>
</tr>
<tr>
<td>HIV Positive</td>
<td>2,953</td>
<td>9%</td>
<td>.04%</td>
<td>48%</td>
<td>43%</td>
</tr>
</tbody>
</table>

All infants born to HIV-infected mothers will test HIV positive at birth because infants carry the maternal antibody. However, not all infants born to HIV-infected mothers are themselves HIV infected. It is estimated that about 15 to 30 percent of these infants will subsequently develop HIV infection (Centers for Disease Control and Prevention, 1995). Other recent studies show a lower, but still widely variable maternal transmission of 12 to 35 percent. The remainder of these infants will seroconvert; that is, their HIV antibody status will change from positive to negative when they lose the maternal antibodies to the virus and begin producing their own. Antibody status of newborn infants, therefore, is an indicator of maternal infection but does not indicate whether the child is HIV infected.
Nine percent of the infants served by the AIA programs were reported as HIV positive at birth and 48 percent were reported as HIV negative. The status of the remainder was unknown.\(^1\) (See Table 2). Fewer programs were able to provide information on HIV status at age 15 months for the target infants. The 1994 data show those programs which collected this information found known HIV infection among 11 percent of the infants; 71 percent of the infants were known not to be infected; and the serostatus of 18 percent was still unknown.\(^2\)

Close to two-thirds (64 percent) of the target infants served had been referred to child protective services (CPS) prior to intake into the program; another 14 percent of the infants' referral status was unknown.\(^3\) The proportion of infants who were referred to CPS prior to enrollment in the program indicated that referral to the program by public child welfare agencies was a common, but not exclusive, entry point into these programs. Significantly fewer CPS referrals were made once families were enrolled in the AIA programs. Only 12 percent of the target infants served had a CPS referral made on their behalf while enrolled in the AIA program (referral status was unknown for 19 percent).\(^4\)

When CPS determines that an infant may be in immediate danger if discharged from the hospital to the biological family, a protective hold can be placed on that infant which places the child in the temporary custody of the child welfare agency. The child remains in temporary custody until a

\(^1\)1992 - 11 programs reporting (n= 962). The data for many is unknown since testing is not a standard practice.
\(^2\)1992 - 15 programs reporting (n=1,264)
\(^3\)1994 - 11 programs reporting (n=1,304)
\(^4\)1992 - 13 programs reporting (n=941)
1994 - 23 programs reporting (n= 3,530)
thorough risk assessment can be conducted and/or another placement arrangement is made.

Hospital discharge at the time of delivery was delayed for 18 percent of the target infants due to a protective hold; 73 percent were able to leave the hospital with their parents or other caregivers with no protective hold being placed; and the protective hold status of six percent of the infants was unknown.25

At the time of program intake, half of the target infants/children were home with their biological parents or with other relatives, while 16 percent were hospitalized and 13 percent in the care of foster parents.26 (See Figure 8). At termination from AIA programs, only three or .2 percent of the target infants/children were hospitalized; the majority were home with their biological parents (51 percent), with relatives (13 percent) or in a foster care home (15 percent). (See Figure 9.)27

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*1992 - 11 programs reporting (n=847)
1994 - 15 programs reporting (n= 2,313)
*1992 - 12 programs reporting (n= 807)
1994 - 24 programs reporting (n= 2,760)
*1992 - 10 programs reporting (n= 230)
1994 - 19 programs reporting (n= 1,170)
Figure 8

Target Infant/Child Placement at Program Intake

- Residential treatment with biological parent: 16%
- Group home or residential care: 1%
- Foster care home: 13%
- Home with relative: 13%
- Pre-adoptive/adoptive home: 1%
- Other/Unknown: 1%
- Hospitalized: 16%

1992 and 1994 Data
Total Number
Infants/Children = 3,567

Figure 9

Target Infant/Child Placement at Termination from A1A Programs

- Group home or residential care: 18%
- Residential treatment with biological parent: 1%
- Foster care home: 15%
- Home with relative: 13%
- Pre-adoptive/adoptive home: 1%
- Other/Unknown: 1%
- Hospitalized: 0%
- Home with biological parent: 51%

1992 and 1994 Data
Total Number
Infants/Children = 1,400
In 1994, AIA programs reported that 2,893 cases had been terminated. Services were completed for about one-third of the clients while 19 percent of the clients chose to terminate services.\(^2^8\) (See Figure 10.) Other reasons for client termination from AIA programs included program violation/noncompliance (i.e., relapse, intent to continue use, refused to cooperate, dangerous behavior), pregnancy terminated, and continued as an active client under a new program model. The average number of months in AIA programs at termination was seven with a standard deviation of 4.3 (and a range of two to 14 months).\(^2^9\)

**Figure 10**

Client Termination from AIA Programs

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services completed</td>
<td>32%</td>
</tr>
<tr>
<td>Client deceased</td>
<td>1%</td>
</tr>
<tr>
<td>Client referred to other agency</td>
<td>6%</td>
</tr>
<tr>
<td>Client's whereabouts unknown/unable to contact</td>
<td>14%</td>
</tr>
<tr>
<td>Client moved out of service area</td>
<td>5%</td>
</tr>
<tr>
<td>Client chose to terminate services</td>
<td>19%</td>
</tr>
</tbody>
</table>

\(^2^8\) 1994 - 28 programs reporting (n=2,893)

\(^2^9\) 1994 - 21 programs reporting (n=2,402)
III. AIA PROGRAM SERVICES

The AIA programs are diverse and operate out of hospitals, community-based child and family service agencies, and state and local child welfare agencies. While each provides a package of services tailored to its specific circumstances, in the aggregate they provided a variety of services to their client families. (See Table 3.) Some of the services are provided directly by AIA funded staff, while others are provided by referral to collaborating agencies. If the AIA program was part of a consortium or multiagency collaboration, the distinguishing factor between services provided directly and services provided by referral was the source of funding. Services paid by AIA funds or matching funds were classified as provided directly by AIA staff.30

The most commonly provided service is hospital or community-based case management. Prior to discharge from hospitals, infants receive the benefit of hospital and, often, child welfare case management to ensure expeditious discharge. For children residing with their families, the family is assigned a worker to assist them in determining service needs and "managing" the network of agencies and people who come together to serve the family. The case manager, who may provide services him/herself as well as functioning as a broker or liaison with other providers, becomes the single identifiable individual to whom a family can turn in times of confusion or crisis. All of the families (biological and caregiver) served by the AIA programs

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30 1994 - 29 programs reported data on direct service delivery \( (n=3,769) \)  
24 reported data on referral to outside services \( (n=2,822) \)
receiving case management, with the majority of those (87 percent) received case
management, with the vast majority of those (87 percent) receiving the service directly from
the AIA program. (See Table 3.) Infant/child development/education was the second most
frequently received service by AIA families (72 percent). More than two-thirds of the clients
served received in-home services (67 percent) and transportation assistance (70 percent). Over
one-half of the AIA clients received food and/or clothing donations (63 percent), parenting
education/support (55 percent), and primary medical care (51 percent). In addition, 31 percent of
AIA clients received HIV screening/assessment and 21 percent received other HIV related
services such as HIV education.31

Overall, the trend in AIA program service delivery is toward the direct provision of supportive
services such as case management, parenting education and support, and some concrete services
(transportation, food, and clothing) and indirect provision of most medical care and drug
treatment through referrals.

As the program has evolved and the challenges of preventing abandonment are better understood,
programs have become substantially more comprehensive. In contrast to 1992, many more now
provide (directly or by referral) infant development screening and assessment (from 29 percent to
45 percent), food or clothing donations (from 31 percent to 63 percent), primary medical care
(from 17 percent to 51 percent), legal advocacy (from 7 percent to 37 percent), housing
assistance (from 22 percent to 33 percent), and infant massage (from 1 percent to 10 percent).

31 1994 - 25 programs reported data on direct service delivery (n= 3,321)
19 programs reported data on referral to outside services (n= 1,768)
### TABLE 3

Percentage of AIA Clients Who Received the Following Services
1994 Data

<table>
<thead>
<tr>
<th>Service Areas</th>
<th>Provided Directly by Programs</th>
<th>Provided by Referral</th>
<th>Total Provided (Direct + Referral)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Management</td>
<td>87%</td>
<td>13%</td>
<td>100%</td>
</tr>
<tr>
<td>Infant/Child Dev't/Education</td>
<td>65%</td>
<td>7%</td>
<td>72%</td>
</tr>
<tr>
<td>In-Home Services</td>
<td>56%</td>
<td>11%</td>
<td>67%</td>
</tr>
<tr>
<td>Transportation</td>
<td>55%</td>
<td>15%</td>
<td>70%</td>
</tr>
<tr>
<td>Parenting Education/Support</td>
<td>46%</td>
<td>9%</td>
<td>55%</td>
</tr>
<tr>
<td>Food and/or Clothing Donations</td>
<td>41%</td>
<td>22%</td>
<td>63%</td>
</tr>
<tr>
<td>Infant Dev't Screening/Assessment</td>
<td>30%</td>
<td>15%</td>
<td>45%</td>
</tr>
<tr>
<td>Peer Counseling</td>
<td>26%</td>
<td>4%</td>
<td>30%</td>
</tr>
<tr>
<td>Pediatric Health Care</td>
<td>25%</td>
<td>21%</td>
<td>46%</td>
</tr>
<tr>
<td>Recovery Support</td>
<td>21%</td>
<td>21%</td>
<td>42%</td>
</tr>
<tr>
<td>Primary Medical Care</td>
<td>19%</td>
<td>32%</td>
<td>51%</td>
</tr>
<tr>
<td>Entitlement Assistance</td>
<td>17%</td>
<td>22%</td>
<td>39%</td>
</tr>
<tr>
<td>Postnatal Care</td>
<td>16%</td>
<td>28%</td>
<td>44%</td>
</tr>
<tr>
<td>Mental Health Counseling</td>
<td>16%</td>
<td>23%</td>
<td>39%</td>
</tr>
<tr>
<td>Child Care</td>
<td>16%</td>
<td>14%</td>
<td>30%</td>
</tr>
<tr>
<td>Prenatal Care</td>
<td>15%</td>
<td>24%</td>
<td>39%</td>
</tr>
<tr>
<td>Housing Assistance</td>
<td>15%</td>
<td>18%</td>
<td>33%</td>
</tr>
<tr>
<td>Legal Advocacy</td>
<td>14%</td>
<td>23%</td>
<td>37%</td>
</tr>
<tr>
<td>Public Health Nurse Visit</td>
<td>13%</td>
<td>2%</td>
<td>15%</td>
</tr>
<tr>
<td>Out-patient Drug Treatment</td>
<td>10%</td>
<td>28%</td>
<td>38%</td>
</tr>
<tr>
<td>Respite Care</td>
<td>5%</td>
<td>9%</td>
<td>14%</td>
</tr>
<tr>
<td>Vocational/Educational Assistance</td>
<td>4%</td>
<td>19%</td>
<td>23%</td>
</tr>
<tr>
<td>Infant Massage/Training</td>
<td>3%</td>
<td>7%</td>
<td>10%</td>
</tr>
<tr>
<td>Residential Drug Treatment</td>
<td>2%</td>
<td>32%</td>
<td>34%</td>
</tr>
</tbody>
</table>
IV. INNOVATIVE SERVICES

The infants and families served by AIA programs are among the neediest clients in the health and human services systems, beset by chemical addiction, HIV/AIDS, poverty, homelessness or inadequate and unstable living arrangements. Infants exposed to drugs and/or HIV in utero often need specialized health care and therapeutic interventions to help them recover from early physical and developmental traumas. Parents typically need assistance with housing and transportation, health care, drug and alcohol treatment, parenting and supportive therapeutic services to help them address the day-to-day challenges of their lives.

The challenge for the AIA programs is substantial. The programs must mobilize and coordinate a variety of services from fragmented health and human services systems, and provide those services to a client population which is wary of the professional community and has little initial use for such interventions.

Based on interviews with AIA program directors and staff and a review of program materials, strategies which constitute the core of innovative AIA services with drug-exposed and HIV/AIDS-affected families have been identified. These include:

- **Interagency collaboration** to coordinate service development and funding between multiple agencies serving the same population;
- **Intervention teams** which bring together professionals from a variety of disciplines in the planning and delivery of services;
• Peer services which use paraprofessionals from the community to provide outreach, education, and supportive services;

• Home-based services which provide educational, supportive, and therapeutic services in the home of the client;

• Culturally appropriate and women-focused services which adapt therapeutic interventions to reflect the cultural and ethnic influences in the lives of families and meet the needs of women, particularly those with young children;

• Coordinated medical and social services case management to reduce medically unnecessary hospital days and expedite hospital discharges to the most family like settings; and

• Legal, policy and program development to promote permanency for HIV-affected children and to help keep children orphaned by AIDS from entering the child welfare system when other resources can be identified.

Each of these innovations is briefly described. The discussions of interagency collaboration, intervention teams, peer services, home-based services, culturally appropriate and women-focused services are presented in greater detail in the earlier Report to the Congress: Effective Care Methods for Responding to the Needs of Abandoned Infants and Young Children (Ramler, et al., 1994). The discussion of coordinated medical and social services case management and legal, policy and program development have not previously been described and draw on quantitative and qualitative data from AIA programs.
Interagency Collaboration

Effective service provision to families living with drugs and HIV must be comprehensive and seamless, and requires far more resources than any single agency can provide. Coordinating the involvement of professionals from multiple systems, therefore, is a key element of effective practice in virtually all of the AIA programs. Management level staff convene in interagency consortia to discuss program policy and funding issues. In 60 percent of the programs, the consortia's lead agency is the AIA funded program, underscoring AIA's critical role in this process.

Seeking to advocate and reduce treatment barriers for their shared families, consortia members address such issues as: housing, substance abuse treatment for parenting women, child care, transportation, and prenatal care. Most of these groups also engage in more intensive activities, specifically generating joint service plans, coordinating referral protocols, and sharing information related to case intake and assessment. Half of the programs adopt collaborative structures, such as combined funding or the co-location of services.

Membership in the interagency groups vary by program, but the core agencies represented are public child welfare, health care, and substance abuse treatment. Other community-based service agencies include housing and early intervention programs and, occasionally, schools, mental health, and probation and parole.

Among the most significant and practical results of interagency collaboration are enhanced case-level information sharing, expansion of knowledge across disciplines, and a broader
range of services for families. Collaboration reduces duplication of services and increases coordination.

Interagency collaboration also challenges program directors to move beyond their agency perspectives and arrive at a more comprehensive view of the client family and the service package. It has been purported to "broaden and stretch people to consider the needs of the whole family unit as opposed to just the baby or just the mother." Consortia members have learned to appreciate and accommodate each other's views of the family. So, for example, the interagency debate about child protection versus family preservation has evolved into a search for strategies to promote child protection and family preservation (Barth, 1994; MacDonald, 1994). The integration of varying professional philosophies has given rise to fundamental changes in program approaches and service delivery mechanisms and promises to last well beyond the operation of most consortia.

The benefits of collaboration do not come without burdens, however. The task of working out a common mission and focus among varying disciplines sometimes generates conflict and frustration and requires a significant expenditure of time. But, despite the burdens, agency directors are committed to the process of collaboration. There is a shared belief that coordination and collaboration offers the best hope of an effective response for these families and enables communities to continue providing core services to the neediest families in the face of growing resource constraints. A sense of crisis, the commitment of the participating individuals, their interpersonal collaborative skills, and the maintenance of clear and open channels of communication are cited as factors critical to the success of collaborative efforts.
When collaboration is close and the service team united, the leverage of certain agencies (e.g., public child welfare) is considered critical. Because AIA programs are voluntary, partnership with court-mandated services provide the necessary leverage in obtaining the client’s compliance with an agreed upon service treatment plan. Some public services are also the gatekeeper to essential resources such as housing, child care, respite care, foster care, and early intervention services.

**Intervention Teams**

Virtually all of the AIA programs use interdisciplinary intervention teams within the agency to deliver services at the individual case level. The staff disciplines most frequently represented on teams are social workers (81 percent) and nurses (67 percent). One-third of the teams also employ mental health clinicians (i.e., psychiatrists, psychologists, counselors), physicians, or early intervention/child development specialists and over one-quarter of the teams include substance abuse counselors or paraprofessional staff. Occasionally, nutritionists, health educators, child care workers, hearing and speech therapists, physical and occupational therapists, and foster parents are also members of AIA intervention teams.

While leadership of the teams is commonly shared among members, it varies depending on what issues take precedence for particular families. So, for example, a nurse might assume leadership of the team for a family with very complicated medical needs, while a social worker might assume the leadership role if parenting and resource needs are paramount. While the size of intervention teams range from two to 20 members, it varies according to the needs of specific families. The median number of team members is four.
The team approach yields benefits for client families, as well as program staff. For families, the participation of an interdisciplinary team of service providers ensures a variety of perspectives, a more holistic assessment of needs and a more complete treatment plan. Team members must relinquish some power to the judgment of the group, which reduces the risk of pre-judgment or bias. Clients who have contact with several individuals are also more likely to find someone with whom they can establish rapport. As one AIA director noted:

A team is able to deal with the multiple worlds of the client. The family support worker is closer to the client and can forge a relationship. She is trusted more easily and is less likely to be taken in or manipulated. The clinician informs the work and supports the family support worker because work in the home is very hard to do alone. The early childhood specialist can provide services directly to the child. Substance abuse counselors provide ongoing education about recidivism. Each can reach the family in different ways.

The team approach is particularly beneficial for families with HIV, where the need for collaboration between medical and social service providers is particularly acute.

Participation on a team is beneficial for staff members as well. Teams reduce the sense of isolation and burden that can result from trying to help families with overwhelming needs in a service poor environment. More than 70 percent of the case managers interviewed stated that teams made their job easier on a day-to-day basis because they felt supported. Workers also noted that they were able to focus on their area of particular expertise while at the same time learn from co-workers from other disciplines.

The most challenging aspects of comprehensive interdisciplinary participation is reaching agreement about role definitions and the service agenda. Forty-one percent of the respondents
witnessed unrealistic expectations of other disciplines, withholding of information, and turf battles on their intervention teams. One-third of the programs noted the difficulty of negotiating conflicts between team members with regard to service priorities so that client outcomes were not adversely affected.

Thirty-six percent of the respondents indicated that frequent meetings and close communication were a key factor in the implementation of an effective team model. Program administrators actively foster effective teams through such team-building activities as routine team meetings, retreats and shared training opportunities, supervision and outside consultation devoted to facilitating team work. Additional factors mentioned as critical to team success are commitment to the families and to the team model, and a team ethic of respect for one another's contributions.

Peer Services

Almost half of the AIA programs employ peer staff who have backgrounds and experiences which parallel those of the clients they serve. In general, peer staff are used as "bridges" between the world of the client and the world of the professional staff.

Sixty percent of AIA programs use peer staff to assist clients in identifying needs and accessing resources. AIA programs also use peer staff as outreach workers and parent educators, as well as role models. Peer staff often "know the grapevine" of the neighborhoods and are successful in locating families who need services and following up with them.
Agency administrators and professional staff emphasize that peer staff should not be used in roles in which they feel uncomfortable or have inadequate training or preparation. There is general agreement that peer staff should not provide mental health, developmental, or medical assessments or case management services or interpret medical information. Professional staff also suggested that contacts with collateral professionals are best managed by other professionals.

AIA administrators select paraprofessionals on the basis of attributes perceived to render them effective in the communities targeted for services. Half of the program directors choose peer staff who are recovering substance abusers and are of the same race as the majority of clients. Other administrators select staff from the larger community or the same neighborhoods and socioeconomic status as the clients served.

The benefit of peer staffing most often recognized is the potency of the relationships that develop between clients and peer workers. Peer staff are considered to be more accessible and less threatening to clients and are therefore able to establish more trusting and supportive relationships. They reportedly have more credibility with clients, serve as very powerful role models, and are able to understand the concerns and issues of the families in a way that enables them to be very effective helpers. Workers who are in recovery from substance use are characterized as having a special effectiveness in confronting denial and recognizing manipulation. Positive relationships with peer staff sometimes transfers to the rest of the program, improving compliance with the treatment plan and increasing the likelihood that education and information are used.
Paraprofessionals seem to be particularly helpful as translators of cultural practices and health beliefs. They effectively communicate information about health promotion, parenting, and resources to clients, while concurrently educating professionals about the clients' culture. Many professionals note the degree to which they rely on paraprofessionals as consultants on culturally competent practices, helping them understand not only the culture of a particular ethnicity, but also the culture of particular neighborhoods and the reality of poverty.

The difficulties associated with the use of peer staff include concerns about peers identifying too closely with the clients' problems and issues, occasional conflict with program recommendations or values, tensions with professional staff, and expectations about workplace behavior. Additionally, many professional staff express concern about their ability to adequately convey the value and necessity of case confidentiality to peer staff.

Training and staff development are critical to the operation of a successful peer program. Several AIA programs conduct four-to-six week training sessions and also employ on-the-job training and buddy systems for new peer staff. Training should include not only content regarding role functions, but also guidelines and expectations about workplace behavior. Equally important is guidance about self-care and relapse prevention for peer staff who may be in recovery. Good supervision of peer staff, clinically and administratively, is a critical element. Also, opportunities for professional development and advancement within the agency help to sustain successful peer programs and serve to enhance peer workers' confidence.
Home-Based Services

Two-thirds of the AIA programs provide in-home services to clients. The staff members used most frequently as home visitors are social workers (72 percent), nurses (40 percent), counselors (33 percent) and peer staff (28 percent). Although the specific services provided in-home varies across the programs, the majority of programs use their home visitors to conduct assessments (61 percent), provide parent education (55 percent), and/or provide case management services (55 percent). Other services include child development, counseling, home health care, and/or training in life management skills.

Provision of in-home services is critical to successful outreach efforts. Many clients have so few resources that the lack of transportation and child care create serious barriers to agency-based services. Because some clients are homeless or transient, outreach in the neighborhoods is essential to finding clients and engaging them in services. For clients who are HIV-positive and have compromised health or a fear of stigmatization associated with office visits, home visits can make otherwise inaccessible services accessible.

The provision of in-home services also improves client assessment and service provision by yielding a fuller picture of the client and his or her circumstances. When assessments are more comprehensive, service plans more realistically reflect the needs and barriers faced by clients. Parenting education and support are reported by many staff as having the greatest impact when provided in clients' homes, the setting where circumstances and family dynamics can readily be observed. Services that are not delivered in the context of clients' lives are often less appropriate and sensitive. With their enhanced understanding of clients' home
circumstances, home visitors are able to inform and improve agency-based service provision by sensitizing colleagues to the clients' needs.

Home visits are also helpful in the development of client/worker relationships. Program staff are able to cultivate better relationships with clients by taking the time and energy to go into their neighborhoods and homes. The effort expended by staff communicates respect and caring to clients.

Home visits are not an appropriate vehicle for all AIA program services. Over one-third of AIA directors and staff indicate that psychotherapy and counseling should not be provided in the home due to a lack of privacy, security or other practicalities.

The most commonly cited problem of home-based services is the threat posed by violent, drug-ridden neighborhoods and homes. The majority of staff believe there is at least some threat to home visitors' safety, which is confirmed by stories of actual and potential life threatening experiences.

Successful home-visiting services depend upon recognition of the taxing and time-intensive nature of home visits. Staff commitment, as well as support and training, are the factors most commonly cited as keys to the success of home visiting. To address safety issues, some programs allow workers to double up or travel with an escort. Small caseloads are also identified as an integral part of successful home visiting components.
Culturally Appropriate and Women-Focused Services

AIA programs serve an ethnically and racially diverse population of women and infants. Consequently, service adaptation to meet the needs of these populations is a crucial element of effective service delivery.

Culturally competent agencies produce environments where the cultural background of client families is acknowledged, respected and reflected in the services. Culturally appropriate services entail a commitment to a fundamental set of values and practices.

The majority of AIA programs embrace the theory and practice of cultural sensitivity. More than two-thirds of AIA staff (69 percent) characterize their agency as racially and ethnically diverse or representative of the clients they serve. Nearly one-half (46 percent) of the programs provide staff training on issues of cultural competence, ranging from formal in-service training to informal consultations with knowledgeable staff. Some programs not only acknowledge cultural and racial differences, but also incorporate elements of cultural traditions into their service models.

Awareness and acknowledgement of cultural differences in beliefs about health and parenting are integral components of a culturally sensitive approach. AIA staff have recounted cases where family disruptions were avoided due to the intervention of staff members who were sensitive to cultural differences. One administrator related:

Medical staff have not always been willing to learn about culture and are not always sensitive to cultural issues. For example, nurses and physicians were unwilling to discharge infants because the families did not have an infant bed, even though the
families' culture and preference was to use a family bed. This was holding up discharges from the hospital....

The social worker in this case was able to educate the medical staff about the cultural difference and to change hospital practices which were delaying appropriate discharges.

An important practice for culturally competent service providers is self-evaluation and taking on the role of learner. Several AIA programs cited instances of differing perspectives between staff and clients about methods of child discipline. Acknowledging differences in attitude and understanding reasons for cultural differences before teaching alternative methods of parenting and discipline results in more effective teaching. One AIA program uses the Effective Black Parenting curriculum which places the use of physical discipline in the African-American community in a historical context and validates community attitudes about discipline prior to the introduction of alternative techniques.

Although culturally competent staff do not necessarily have to share their clients' ethnicity, the use of ethnically representative staff is beneficial. Clients are provided with positive role models who are similar to themselves.

Although cultural sensitivity is the stated goal of most AIA programs, challenges to achieving it are readily cited. One-third of the programs reported that recruitment of ethnic minority staff with appropriate education, experience, and licensing is difficult. Staff attitudes are also cited as a source of difficulty. Where problems arise between staff and clients due to racial and ethnic differences, AIA programs typically address the issues through team consultation or individual staff counseling.
Matching community services to the needs of women is an important activity for many AIA programs. By developing women-focused service models, these programs help bridge gaps and reduce barriers to services.

The provision of transportation and child care is a priority for AIA programs who serve women with children. Over two-thirds of the programs either provide or arrange transportation and close to one-third provide or arrange child care to enable mothers to attend appointments and program activities. Home visiting and the provision of multiple services at a single location also help reduce barriers to services. Some AIA programs have also developed a model of family care which provides services to the siblings of target infants.

Some AIA sites incorporate women’s health care services (i.e., family planning, obstetrics and gynecology) into their program models, contending that women’s basic needs must be fulfilled before addressing substance abuse recovery. Empowerment and self-esteem building were also cited as essential components of a woman-focused approach. Many AIA programs conduct group work with women clients, which is particularly effective in decreasing isolation and providing a forum for shared experiences and resources. Some programs address the many demands placed on women who are primary caretakers by providing special recognition events, such as Mother’s Day celebrations.

Substance abuse treatment modalities for women need to address conditions which particularly affect women, such as low self-esteem and depression. Treatment that provides more support to them than traditional approaches are critical.
Educating other professionals about the issues and demands faced by women is another aspect of providing women-focused services. AIA staff members describe helping other professionals understand the difficulties faced by clients, such as a missed clinic visit for one child due to a lack of child care for the other five or the burden of taking public transportation to a clinic for a mother who does not own a stroller.

The result of structuring programs to meet the needs of women with children is that the women are able to participate. However, AIA programs do not operate in a vacuum; they must rely on services offered by other agencies in the community which are often non-existent. Securing essential resources (i.e., housing, child care, transportation), and locating services such as substance abuse treatment and job training programs which serve women with children is problematic. The lack of safe and affordable housing can greatly diminish any gains a woman has achieved while receiving services and may force her to return to unstable, unhealthy or even violent situations. Finally, women who are substance abusers and have exposed their children to drugs are often stigmatized by the public, as well as the service community.

Coordinated Medical and Social Services Case Management

AIA programs who serve infants who have been exposed to drugs or HIV have been instrumental, in various ways, in expediting the discharge of these children from the hospital. Some of the AIA projects fund transitional living facilities, which provide temporary housing for infants while permanent placements with biological parents or, alternatively, foster families are secured. The facilities serve communities where there is a rampant, chronic drug problem,
an overburdened child welfare system, and a critical lack of licensed and trained foster parents to adequately care for drug-exposed or HIV-infected children.

Some hospitals report the birth of infants who test positive for drugs to local child welfare departments, who may in turn refer the infant and families to AIA programs. AIA programs work intensively with the mothers to maintain custody of their children. Workers from the programs assist mothers in identifying their needs, enrolling in appropriate services, getting to appointments, and parenting their children appropriately. Many AIA programs make contact with the mother before she is released from the hospital and make arrangements to see her at home within a day or two of leaving the hospital.

Another AIA program operates out of an intensive care nursery. The program's social worker screens all babies in the nursery. If there is a positive toxicology screen or a history of substance abuse during pregnancy, contact is made with the mother within 24 hours and a home visit is scheduled to occur within the week. The social worker determines if the child should go home with the mother. If this placement is clearly inappropriate, the program works with the child welfare agency or, alternatively, the hospital to find an appropriate home, address the legal issues involved and provide specialized training to the foster parent as quickly as possible. AIA staff may help in recruiting appropriate homes for the children when the county has not been able to locate them.

If AIA programs did not exist, it is probable that the children would be retained in hospital settings for longer periods of time, due to the continuing lack of appropriate foster care homes.
It is also more likely that infants would not be placed as frequently with their biological parents. Project Prevent in Atlanta, Georgia; Hudson's Cradle in New Jersey and SPARK in Philadelphia have estimated the cost savings and highlighted many of these innovative service delivery approaches (see AIA Programs and Case Studies -- Section V of this report).

AIA programs conduct frequent training for the medical and child welfare communities, as well as other community agencies, foster parents, and birth parents. More timely discharges of infants are theorized to be the result of a greater awareness on the part of hospital and child welfare personnel of the detriments of lengthy hospital stays for infants as a result of their training. Currently, hospital and child welfare staff, of their own accord, keep themselves apprised of the census at AIA programs and refer clients and families expeditiously.

Legal, Policy and Program Development

In response to the increasing number of single parent women with HIV/AIDS in this country, AIA programs have pioneered legal and social services to assist these families in developing permanent plans for their children. By enabling parents to make custodial decisions for their children and providing critical psychosocial support to all members of the families, AIA programs are helping to alleviate the added stress caused by instability and insecurity, and reducing the number of children unnecessarily placed in State custody and foster care.

Societal attitudes, coupled with the common feelings of anger, frustration, fear, and denial associated with HIV/AIDS, make it exceedingly difficult for parents with HIV/AIDS to
disclose their health status to their children or to take the necessary steps (e.g., legal advice) to ensure permanent, stable custody of their children. Additionally, many parenting women with HIV/AIDS face a daily struggle and immediate concerns for housing, food and medical care, making it virtually impossible for them to plan for their children’s future.

Further exacerbating the problem, courts are typically overburdened with cases and the lack of appropriate resources, and attorneys and family court judges often lack training and education in issues related to HIV/AIDS. Many women with HIV also resist any involvement in a legal system with which they may have had adversarial experiences related to crime, domestic violence or substance abuse. Finally, given the episodic nature of the disease (e.g., women may be reasonably well for years after diagnosis but may have periods of severe illness), the custodial arrangements that have traditionally existed provide less than ideal options for parents and often require extensive, complicated legal involvement. Formal kinship or foster care arrangements, for example, require the biological parent to relinquish legal custody of their child to the child welfare agency while they are alive; yet caregivers in informal arrangements, which allow the parent to retain legal custody over the child and avoid state involvement, are generally not eligible for financial or psychosocial support and have no legal caregiving authority after the parent’s death. Guardianship, an option which provides some security to the parent about their child’s future, enables the parent to legally designate a guardian for their surviving child. However, there are no provisions for the child if the parent becomes too sick to provide care, and, following the parent’s death, the designated guardian must await approval of the court, which may not be granted. Traditional adoption requires a parent to

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relinquish all parental rights for the security of knowing that their child has a permanent home, and often entails a lengthy and heavily regulated process.

To help clients overcome these barriers, 37 percent of AIA programs have developed mechanisms for assisting clients with the legal and psychosocial aspects of permanency planning, and have been instrumental in enacting legislation and administrative policies to facilitate this process. AIA programs in Illinois, New York, Connecticut, and Florida, for example, helped pass legislation for standby guardianship which allows parents to appoint a guardian who assumes guardianship duties for their children only upon the parent's death, physical or mental incapacity, or consent. This ensures stability and permanency for a child following the death of a parent, and gives parents assurance concerning their children's future welfare. The bill in Illinois also provides for guardianship for a limited duration which enables parents to designate a person to act as guardian for their children during periods of incapacity for up to 60 days without court intervention.

Even with these alternative arrangements, however, women with HIV/AIDS need legal assistance and advice in order to determine and implement the best plan for their families. To address this need, SPARK, an AIA project in Philadelphia, PA, established an agreement with the AIDS Law Project of Pennsylvania to provide free, on-site legal services to HIV involved families including custody planning, power of attorney, living wills and wills. SPARK case managers and home visitors provide a bridge to legal services for their clients, and the Law Project staff provide legal education to SPARK staff and clients and a linkage to the court system. Similarly, the AIA Mothers Project at Yale University collaborates with the Yale Law
School HIV Legal Clinic to provide home-based legal assistance to clients working towards permanent plans for their children.

To inform other agencies about issues related to permanency planning, SPARK staff developed (and plans to disseminate widely) a manual, *Building Bridges: How Social Service Providers Can Help Parents with HIV/AIDS Make Appropriate Custodial Decisions for Their Children*, to help agencies serving families affected by HIV/AIDS build a legal services delivery component and identify and help families access appropriate HIV/AIDS legal services necessary for successful custody planning for their children. Also, the Mothers Project developed a handout for other agencies regarding the pros and cons of various legal options available to HIV infected parents and their children.

Other AIA projects, including demonstrations at Leake & Watts and Society for Seamen's Children in New York City, and The FaCT Model Project at the Maryland Department of Human Resources, provide extensive counseling and assistance to birth parents on early permanency planning for their children and, failing that, find ways to expedite adoption planning. Additionally, these programs offer supportive services to affected children and substitute caregivers throughout the often emotional and traumatic transition process. The AIA programs help families make critical permanent plans for their children who otherwise might enter the overburdened foster care system and perhaps suffer psychosocial and emotional trauma caused by the instability and insecurity of having no permanent caregiver following the death of their parents.
V. AIA PROGRAM AND CASE STUDIES

Project Prevent

Program Description

Project Prevent, an AIA demonstration project initiated in July 1991, is based at Grady Memorial Hospital in Atlanta, Georgia. The program was developed in response to the growing incidence of "boarder babies" in the nursery -- those babies who stay in the hospital, for social reasons, after they are medically ready for discharge. The most common cause of boarding at Grady is maternal substance abuse, particularly crack cocaine. The goal of the project is to prevent the abandonment of newborns in the special care nurseries at the hospital.

Project Prevent adopted a three-tiered approach in an effort to reduce the incidence of drug-exposed and medically needy babies. The Pre-Team, through referrals and outreach, targets pregnant women in the community who have a history of substance abuse and are at risk of delivering a medically needy baby.

The Post-Team, working out of Grady's special care nurseries, identifies infants admitted to the NICU with a history of maternal substance abuse. The team, throughout medical admission, provides intensive services to the mother and attempts to stabilize her situation so that the baby is able to remain with the family when medically ready for discharge. If this is not possible, the team works closely with other agencies to find placement and delay
boarding in a very expensive and institutional setting. Upon discharge from the hospital, developmental and physical health services are coordinated with the families for one year.

The Support Team assists both Pre-Team and Post-Team clients to overcome whatever needs or barriers to care and recovery they may identify (e.g., child care, drug treatment, spiritual support, self enhancement, parenting skills, and male support/education group). The services also incorporate a new component, STD Prevention and Education, that explicitly addresses the issues surrounding the high-risk behavior of this population and integrates the available service systems. Other services that are offered by the project include: psychosocial services, case management, referrals, intensive home-based services, health education, child care, recovery support, life skills and parenting groups, children's support groups, entitlement assistance and transportation. Multi-agency collaboration is a vital element of the program, with staff coordinating services with public child welfare, the courts, drug treatment agencies and the police. Child care is provided by families from the community who are recruited and trained to support Project Prevent.

Peer addiction counselors, who are recovering addicts, and child development workers are recruited from the neighborhoods in which they work and comprise a core component of this program. Other staff members include the director, social workers, a clinical supervisor, a research specialist, a disease intervention specialist and a corps of volunteers.
Adrian

Adrian is a 39 year old woman who used to run the streets, using alcohol and crack cocaine. She recently gave birth to a son, who she has since decided to raise. Only three months prior, Adrian had planned to give her baby up for adoption or abandon him in the hospital where he was born. Her child was the unanticipated result of a union of convenience, a woman selling her body for drugs and an amenable stranger. She had no desire for the responsibilities of motherhood.

For the first six months of her pregnancy, Adrian prowled back alleys and city byways searching for a hit, sleeping wherever she could find a spot. With only the clothes on her back and no money in her pocket, her focus was on reducing her drug craving. She knew nothing about Medicaid and assumed that her poverty would preclude medical care.

In her sixth month, the Health Department suggested to Adrian that Project Prevent could assist her to obtain Medicaid and food stamps. She was in the office soon after talking to the triage worker. At the outset, Adrian continually cancelled her appointments at Project Prevent and had no intention of participating in drug treatment. With her options dwindling, however, she did finally return to the office. The triage worker, keenly aware of Adrian's history, introduced her to her caseworker within moments of her arrival.

Arrangements were made for her to stay in a homeless shelter for women that night, and an appointment with a treatment facility was arranged for a few days later. The worker knew that Adrian was likely to take off again, so she escorted her to the shelter. The worker also took Adrian to her obstetrics appointment, contacted her at the shelter several times during the subsequent days and nights, and accompanied her to her interview for drug treatment. After a delay of about ten days, Adrian was admitted to a residential drug treatment facility, where she was able to kick her habit.

Adrian is no longer a woman on the streets looking for her next high. She is a woman who has embraced her son with love and tenderness, and with awareness of the responsibilities she is about to face.

Outcomes of Project Prevent

As of March 1995, over 1,800 pregnant women have been referred to the program with the average month of referral at the fifth month of pregnancy. All of these women receive their medical care at Grady Memorial Hospital in Atlanta, Georgia.
Prior to Project Prevent, there was at least a 35 percent incidence of cocaine-positive infants of the total number of admissions to the neonatal intensive care nurseries at Grady Memorial Hospital. There was a marked decrease to 11 percent after the first year which has been maintained over the next three years. (Drug exposure is determined by mother's alcohol drug history during pregnancy and/or mother/babys positive urine drug screen test at delivery.)

Close to three-quarters (72 percent) of the infants born to women who participated with Project Prevent during their pregnancy were normal birth weight (5.5 pounds) compared to 59 percent of those infants whose mother did not participate with Project Prevent during pregnancy.

In the year prior to Project Prevent, there were 52 infants that "boarded" (medically ready for discharge but do not have an appropriate placement) for a total of 1,006 days. Since the beginning of the program, there has been a decrease in the number of boarder babies and a reduction in the number of days boarding. The number of boarder babies in FY 1991-92, FY 1992-93, FY 1993-94 and FY 1994-March 1995 were 29, 20, 31, and 30 respectively for a total of 116 boarder infants. The total cost of the 116 boarder infants was $3,649,500. Eighty-two percent of the infants board for less than 30 days; however the six percent of infants who boarded greater than 60 days account for over 38 percent of the total boarding cost due to their complex medical needs and delay in placement. (See Table 4.)
Figure 11 presents the projected cost of caring for infants admitted to the neonatal intensive care had the cocaine incidence remained unchanged (at 35 percent). The actual cost based on the lower incidence of cocaine-exposed infants reflects the effects of Project Prevent intervention. Using this method, the estimated total hospital cost savings for three years (7/91-6/94) is $51,862,530. (Note: These findings are preliminary.) Subtracting the program costs for these years (in addition to the baseline year) of $2,137,500 nets an approximate fiscal savings to society of $49.7 million. Even if Project Prevent is directly responsible for only 20 percent of these savings it would have saved nearly eight million dollars. Perhaps as important, Project Prevent has the vision and collaborative relationships with other service providers to further reduce unnecessary medical costs. Project Prevent staff indicate that a treatment foster care program for medically-involved children could further reduce these costs and are working with others to encourage its development.
Figure 11

Financial Impact* of Project Prevent in the NICU
Grady Memorial Hospital
Atlanta, Georgia

Note: These findings are preliminary; Cost information is based on total medical and boarding charges incurred at Grady Memorial.

Source: Project Prevent, Atlanta, GA
Hudson Cradle, A Home for Infants

Program Description

Hudson Cradle, A Home for Infants, operates a transitional residence for boarder babies and medically fragile infants and toddlers who are under the supervision of New Jersey's Division of Youth and Family Services (DYFS), the State's child protection agency. The AIA-funded project, which occupies a nine-bed converted brownstone and is affiliated with the Jersey City Medical Center (JCMC), began operations in late 1991 when it removed its first medically cleared child from one of the hospital's wards.

Hudson Cradle's main goals are the following:

- to avoid the prolonged, costly and unnecessary boarding of infants and toddlers at Jersey City Medical Center and other area hospitals;
- to care for the daily needs of these very young children, while focusing especially on their health and developmental issues; and
- to work with their parents and other caregivers around family reunification or placement.

Hudson Cradle provides comprehensive and compassionate care to babies. Hudson Cradle infants require a temporary home due to family problems including substance abuse, homelessness, mental health illness, poverty and child abuse/neglect. The babies very often have special needs related to prenatal drug and HIV exposure, prematurity or low birth weight.

Hudson Cradle recognizes the diversity of the Hudson County cultural community and to this end, the staff provide culturally sensitive outreach, education, training, assistance and support. Hudson Cradle staff include an on-site project coordinator, a registered nurse, a social worker,
Antonia
The following example is typical of the children and families Hudson Cradle works with and the services provided. Baby Antonia, one of Veronica’s four children, was born at St. Barnabus Medical Center in the spring of 1994. She was born prematurely at 35 weeks gestation, weighing just over five and one-half pounds. She had a patent ductus arteriosis (the heart’s ductus arteriosis normally closes shortly after birth), which was treated unsuccessfully with the medication Indomethacin. Her urine tested positive for cocaine.

Antonia’s mother, Veronica, was employed as a school bus aide, she used drugs, including cocaine and marijuana. Her three children reside with their father in Newark. Veronica lives with Antonia’s father, Joe in Jersey City. Joe works full-time as a bus driver. Joe and Veronica lived in the Journal Square area of Jersey City. The referral to Hudson Cradle was made by the Division of Youth and Family Services’ Bayonne Office.

Antonia was admitted to Hudson Cradle in mid-July and resided there for approximately seven months. During this time, Hudson Cradle staff provided her with residential child care, nursing, and developmental services. She received Lasix medication to help prevent congestive heart failure. She required medical follow-up at the Greenville Pediatric Clinic, Jersey City Medical Center Special Needs Infant Clinic, and Jersey City Medical Center Pediatric Cardiology Clinic, and special testing at Children’s Hospital of New Jersey. In addition, because Antonia came to Hudson Cradle somewhat irritable and “stiff” she received physical therapy two to three times a week at Hudson Cradle through the Bayonne Visiting Nurse Association and early intervention services through Building Blocks. Other agencies involved with Antonia (with care coordinated by Hudson Cradle), included Division of Youth and Family Services, Special Child Health Services, Medicaid, WIC, Child Placement Review Board, and Hudson County Superior Court.

Hudson Cradle’s social worker provided twice weekly counseling to the parents who had issues related to substance abuse and family violence. She assisted with housing (identification and application) and referral to addiction services. She helped with job finding when both parents became employed, including interview role playing, resume development, and potential job identification. She encouraged and supervised parental visits at Hudson Cradle.

Antonia was discharged from Hudson Cradle in mid-January, 1995 to her grandmother (a Jersey City resident). Discharge teaching centered around developmental and health related matters. Physical therapy and early intervention services were to continue. Antonia’s immunizations were up-to-date. Her medical status was stable. In April, follow-up revealed Antonia continues to reside with her grandmother and is “doing well.”
three licensed practical nurses and 12 infant caregivers who provide 24-hour, 7-day-a-week care while children stay at the facility. Besides residential services, the project primarily offers case management, family support, medical care, developmental evaluation and early intervention.

Outcomes of Hudson Cradle

Since late 1991, more than 80 children have been referred by DYFS and stayed at Hudson Cradle's facilities. Their average stay has been two and a half months. As of last count, one in five of the children discharged from Hudson Cradle is living with a parent; one in six, with another relative; and another one in six, in an adoptive or pre-adoptive home. The rest, less than half, are still in foster homes.

Hudson Cradle's work with these cases will ultimately result in: savings; decreased child welfare costs when family members are reunited; lower social welfare expenditures when parents become more self-supporting; fewer medical care costs when chronic and/or congenital health conditions are resolved; and in reduced special education expenditures when children's developmental delays are evaluated and early intervention services are provided in a timely manner.

In the near term, however, the project has already had a measurable fiscal impact -- one that extends well beyond the direct assistance being provided to its clients. The impact results from the project's influence in helping to change state, local and hospital policies and procedures to speed up the decision-making process, and the service delivery system's response to, each medically-cleared infant being held in a hospital bed awaiting discharge to an appropriate family
member or placement resource. The cumulative effect of these changes may end up being of greater consequence to the area's boarder babies than the direct provision of project services to targeted clients.

One measure of Hudson Cradle's overall near-term impact is the change in the average hospital stay of boarder babies at JCMC since late 1991. To conduct this analysis, data were extracted from a monthly boarder baby census compiled independently by JCMC's social work department, for the period between October 1991 and April 1995. These data identify, month by month, which children were staying at JCMC and when each was born, was most recently admitted, was initially cleared for discharge and was finally discharged from the hospital. By aggregating the segments describing each child's hospitalization across the months that s/he was an inpatient, the local evaluator was able to construct a unique record for each child which designates:

- the month in which the child was first determined to be medically ready for discharge;
- the child's age at the time s/he was medically cleared; and
- how long the child remained an inpatient after being deemed ready for discharge.

The six-month interval between October 1991 and March 1992 - when the project was just getting started operationally, served as a baseline and was used to compare how long children stayed beyond their date of medical clearance during that time, with how long those who were medically cleared for discharge in each succeeding month remained on site. These data are
shown graphically in the Figure 12, in which the bars represent the number of children under four years of age who were medically cleared during a particular month and the line represents the average number of days that these children remained on site after being cleared that month. The average unnecessary stay of infants and toddlers at JCMC has dropped substantially, with the advent of Hudson Cradle, even as the number of medically cleared children staying on site has risen erratically.

Figure 12

Medically Clear Children and Mean Hospital Stay After Being Cleared
Jersey City Medical Center
(In-patients age 0-3 years, October 1991 - March 1995)
The average medically-cleared stay of children under four years of age at JCMC fell from 30.15 days during the baseline period to 18.39 days in the twelve months that followed, 16.61 days the year after that and 17.26 days during the latest 12 month period (through March 1995).

Estimating the savings that have resulted from reducing the length of unnecessary hospital stays is a simple matter of multiplying the number of children medically cleared during a period by the mean number of days that their stays have been shortened by the per diem cost of inpatient care. JCMC has determined that the current daily cost of care in its pediatric wards ranges from $800 to $1,000 and that strictly custodial care costs about $575 per day. The cost per day of care for a JCMC boarder baby probably falls in between the custodial level and the low end of the range for regular care -- or currently between $575 and $800. (Cost inflation at the hospital has averaged about seven percent a year for the past three years.)

To the extent that Hudson Cradle's emphasis on identifying potential boarder babies early on and expediting their release from the hospital to a family member or into foster care has helped influence how policy makers and line workers now go about their business, even in cases which do not end up being referred to Hudson Cradle for residential care, this change in the system has contributed to the following savings to JCMC:
TABLE 5

Estimated Savings from Reduced Boarder Baby Stays  
(Jersey City Medical Center, 10/91-3/95)

<table>
<thead>
<tr>
<th>Time Period</th>
<th># of Children Medically Cleared</th>
<th>Avg. Stay After Being Medically Cleared</th>
<th>Decrease in Stay from Baseline Period</th>
<th>Avg. Cost Per Day of Pediatric Care</th>
<th>Estimated Annual Savings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline 10/1/91-3/31/92</td>
<td>33</td>
<td>30.15</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Year 1 4/1/92-3/31/93</td>
<td>75</td>
<td>18.39</td>
<td>11.76</td>
<td>$500-$700</td>
<td>$441,000-$617,400</td>
</tr>
<tr>
<td>Year 2 4/1/93-3/31/94</td>
<td>103</td>
<td>16.61</td>
<td>13.54</td>
<td>$535-$750</td>
<td>$746,121-$1,045,965</td>
</tr>
<tr>
<td>Year 3 4/1/94-3/31/95</td>
<td>116</td>
<td>17.26</td>
<td>12.89</td>
<td>$575-$800</td>
<td>$859,763-$1,196,192</td>
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</table>

The total hospital savings during the first three years of the program (4/1/92 - 3/31/95) are estimated to be $2,046,884 - $2,859,157 or between two and three million dollars. Subtracting the program costs for these years (in addition to the baseline year 10/1/91-3/31/92) of $1,575,000 nets an approximate fiscal savings of between $471,884 and $1,284,157.
Supporting Parents at Raising Kids (SPARK) Program

Program Description

SPARK (Supporting Parents at Raising Kids) is located at Medical College of Pennsylvania (MCP)/Hahnemann University in the city of Philadelphia, which has the eighth largest census of AIDS cases in the U.S. Families served by SPARK typically have the following characteristics: an indigent African-American or Latina women who is the single head of the household, is raising two or more children, has a limited education, is either unemployed or subsisting in a low-wage job, has few support systems and often lacks transportation or telephone, is surrounded by the crime and chaos of inner-city life, has a history of substance abuse or is currently using drugs, and has or is at risk for HIV/AIDS. Increasingly, women referred to the SPARK program also have a multitude of psychobiosocial problems, e.g., addiction relapse, homelessness, domestic violence, and mental health issues, and often have other children in out-of-home placement.

The core component of the SPARK program is intensive home visitation with "wrap-around" services which include: family and individual counseling, social services, developmental screening and referrals for children, transportation, emergency funds, parenting classes and support groups, case management, and nutrition education and counseling. Using a team approach, services are provided by three case managers, three community representatives (peer home visitors) and a child development specialist. To more fully address the complex medical, psychosocial and economic needs of their clients, SPARK facilitates linkages with
community resources and collaborates with other programs from MCP/Hahnemann and other agencies which provide:

- health services for HIV infected women and their children;
- outpatient and partial hospitalization drug treatment for pregnant and postpartum women and their children;
- anonymous HIV testing and educational outreach to the community;
- on-site legal services to HIV involved families; and
- psychiatric evaluations and treatment.

To ensure that collaborative efforts offer clients optimal care with minimal duplication or gaps, staff from SPARK and the collaborating programs have monthly joint case conferences and work together to develop joint policy and procedures. Team meetings with the primary counselors also occur as needed. The goal of the intervention is to decrease child out-of-home placement or, in cases where placement is necessary or has already occurred, to increase family reunification or the development of a permanent plan for the child. To accomplish this, SPARK seeks to enhance the capacity of families to help themselves and their children by providing concrete and emotional support.
Theresa

Theresa is one of many SPARK clients who faces multiple struggles. At 23, she is poor, a recovering drug user and the mother of three children under the age of five. She is also suffering from AIDS-related symptoms. When Theresa was referred to the SPARK Program two years ago, she was in need of drug treatment and ongoing medical care for herself and her children. Theresa had few support systems and, though she loved her children, often took her frustrations out on them by being physically and verbally abusive. Already, there were signs that Tisha, the five year old, was assuming a parental role in the care of her siblings and mother. To address her many needs, a SPARK case manager met with Theresa weekly to facilitate services for her and help her develop more appropriate coping skills. Additionally, a SPARK home visitor focused on helping Theresa attain permanent housing and, along with a child development specialist, assisted Theresa in developing new parenting skills.

Recently, Theresa became obsessed with her HIV status and fears of future debilitation. Primarily, she worried that her children would be taken from her should she become sick. When the intensity of her fears began to take precedent over everything in Theresa's life, her case manager coordinated a referral to an affiliated out-patient psychiatric department. The case manager accompanied Theresa to her first appointment with the psychiatrist. Following this initial assessment, medication was prescribed and monthly follow-up appointments with the psychiatrist were scheduled. Additionally, Theresa continued to meet with her case manager on a weekly basis, and collaboration between the case manager and psychiatrist became a routine component of Theresa's care.

Outcomes of SPARK

Success in a program like SPARK must be measured by small steps and accomplishments in the face of devastating personal, family and societal situations. Theresa's problems have not been eliminated. Nonetheless, because of her involvement with SPARK and its collaborating programs, her needs are fewer, her resources richer, and her ability to care for herself and others is greatly increased. She has made many strides toward developing a care plan for her children that will keep them from entering foster care following her debilitation and death.
SPARK currently provides services to 80 women and their families. Since its inception in 1990, the program has served a total of 195 women and their families. After ten months in the program, clients generally reported significantly increased social support, greater access to services (e.g., transportation, support groups, parenting classes, and baby furniture and toys), and decreased psychological distress. The increased social support, however, was not reported at 16 months when services ended. This may indicate a need for additional, ongoing services or for enhanced support services in the community. The SPARK intervention did not result in a decrease in out-of-home placements, which may be due to closer monitoring of families in the program; however, children of women in the program who were in out-of-home placement were more likely to live with family members as opposed to foster care providers. Also, approximately 20 percent of women in the program whose children were in out-of-home care had their children returned to them, compared to only two percent of women in a control group who only received standard, center-based social services. These findings indicate that, although more controlled research is clearly needed in order to determine the most effective interventions and their long-term effects, services provided by AIA programs like SPARK are effective in helping clients access necessary services and identify family members to assist with the care of their children rather than relying on the overburdened foster care system, and, when necessary, helping children return to their biological parents.
VI. CONCLUSION & FUTURE DIRECTIONS

The AIA program is a demonstration program intended to develop innovative and cost-effective approaches to serving infants who are drug- and HIV-affected and at grave risk of being abandoned. These children began life with serious developmental risk: one-quarter were born prematurely and approximately one-quarter were identified as low birthweight; 44 percent were substance exposed; and nine percent were HIV infected. The case studies contained within this report illustrate that these infants routinely risk prolonged, costly, and developmentally hazardous hospital stays. They also risk the possibility of long spells of impermanence in foster care.

The mothers served by AIA programs also experience extreme adversity. Eight percent of the mothers served were either homeless or incarcerated and more than one-third did not graduate from high school. More than one-third were receiving AFDC at the time of program intake, with mean annual incomes well below the Federal poverty level. Forty-one percent of the mothers with children older than the target infant were reported to have one or more children removed from their care due to child maltreatment. Their health status is poor: half of the women received late or no prenatal care; the majority had evidence of drug or alcohol use during pregnancy and more than half are currently identified as crack/cocaine users; and they are one hundred times more likely to be infected with HIV than women in the United States, overall.

The need for services is obvious, and AIA programs have responded with comprehensive programs in hospital and community settings characterized by a case management approach and the use of multi-disciplinary, multi-agency models of care. The 31 service demonstration
projects represented in this report are diverse, operating out of hospitals and clinics, community-based agencies, and child protective service agencies. While they each provide a unique package of services, they have all added to the comprehensiveness of services available by creating referral pathways or, as needed, the services themselves. Most significantly, these programs have created systems change through the development of a service continuum to increase expeditious hospital discharges, legal developments for children affected by AIDS, and permanency planning.

Cost Effectiveness
The AIA Program is providing direct services and also creating program innovations that can benefit other service providers. These programs are endeavoring to save local, state, and federal resources that would otherwise be consumed in order to pay for the high cost of repeat births of drug and HIV-affected children remaining unduly long in hospital and child welfare services.

Preliminary evidence on the cost savings of programs that coordinate medical and social services case management is encouraging. Data on the cost effectiveness of legal, policy, and program developments to promote permanency for HIV-affected children and to help other children orphaned by AIDS from entering the child welfare system are not yet available but can also be expected to substantially reduce unnecessary expenditures.

Although the evaluations cannot precisely indicate the proportion of savings due to the AIA programs' activities, the evidence suggests that they have served to catalyze a cost-effective approach to services by other participating programs. The impact of such system change goes
beyond the direct benefits received by AIA program clientele. Through the expanded responsibility of the AIA Resource Center to disseminate information about AIA services to state and local child welfare agencies, these innovations will continue to be adopted and their benefits will multiply.

**AIA Program Development and Innovation**

The AIA Programs are continuing to develop. Between 1992 and 1994 their comprehensiveness increased markedly. They have developed important new legal services and alternatives for expediting permanency planning. This history of innovation is likely to endure as programs continue to pursue more prompt and less adversarial approaches to achieve permanency for children. The data in this report demonstrate the commitment of AIA programs to understanding their clientele and services. Future evaluation efforts will provide additional information about aggregate client outcomes. In the interim, we have considerable evidence from individual program evaluations to suggest the continued importance of the AIA program. The AIA programs offer a vision of the possibilities of comprehensive, coordinated, multidisciplinary, and flexible services that can help guide the far larger child welfare system.
REFERENCES:


National Institute of Allergy and Infectious Disease (1994). Pediatric AIDS.


