

**ADDRESSING THE NEEDS OF THE NEEDIEST:  
THE FIRST TEN YEARS OF THE ABANDONED INFANTS ASSISTANCE PROGRAM**

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## SUMMARY

The Abandoned Infants Assistance Act (P.L. 100-505) was introduced in 1988 to address the serious problem of providing care for the growing number of babies being abandoned in hospitals, a problem that was a direct consequence of the emerging epidemics of cocaine use and HIV infection. Funding provided through this Act has supported the development of national demonstration programs designed to address the well-being, safety, and stability of these children, while decreasing their risk of abandonment. The purpose of this paper is to examine the effectiveness of the initiatives spawned by the Act and to describe ways in which the Abandoned Infants Assistance (AIA) programs have had a positive impact on the lives of children and their families.

There are presently 34 AIA programs throughout the country providing services to families affected by substance abuse or HIV/AIDS. To date, the programs have served over 10,000 individuals, with substantial improvements in the lives of children and a dramatic reduction in the problem of “boarder babies”:

- In Newark, New Jersey the length of time children board in hospitals has decreased by 77%; and in Atlanta, boarding costs for babies whose mothers entered the program before they gave birth were less than a tenth of the costs for other babies.
- Parents are better able to care for their children. In Los Angeles, 84% of parents who entered drug treatment were clean and sober at the time of termination from the program; the programs in Philadelphia and New York City have documented decreased rates of depression among women enrolled in the programs; and, data from the program in Oklahoma City suggest a substantial reduction in the likelihood that parents will abuse their children.
- Improved care is affecting the lives of children. In New Haven, Connecticut, children in the program are now getting the health care that they previously lacked and there has been a substantial decrease in the rate of child abuse and neglect.

With support, children are now more often able to live with their biologic families, and mothers who previously had children removed from their care are raising their own children. Programs have been instrumental in helping parents with AIDS plan for the long-term care of their children and avoid the disruptions that these children will face.

Unquestionably, the demonstration programs initiated by the Abandoned Infants Assistance Act have had far-reaching effects on the lives of children well beyond solving the problem of boarder babies. The programs have done away with old concepts of addressing the needs of mother and child separately, and instead, have developed unique models of care that provide coordinated, family-focused services. Expansion of these programs can significantly affect the lives of more children throughout the country who will suffer the consequences of their parents’ drug abuse or HIV infection.

MOMS ARE VERY GOOD IN LIFE  
AND YOU REALLY NEED A MOM IN LIFE  
IF YOU DON'T YOU'LL BE VERY, VERY SAD IN LIFE  
BUT YOU'LL GET OVER IT IN LIFE.

#### Child of a mother with AIDS

The final line of this verse expresses both the sadness and optimism of a 13-year-old daughter of a woman with AIDS. What, however, can really be expected for such children, and what might be the consequences for children growing up in families affected by AIDS and drug abuse?

#### CHILDREN CAUGHT BETWEEN TWO EPIDEMICS

Children can both benefit and suffer from the experiences of their parents, and in the 1980s in the United States, two new and overlapping epidemics -- cocaine abuse and AIDS -- emerged and continue to have dire effects on the lives of hundreds of thousands of individuals. The statistics on the number of individuals abusing drugs or infected with HIV fail to emphasize the extent to which these epidemics affect the lives of children. For parents addicted to drugs or experiencing the physical and psychological consequences of HIV disease, it is often difficult to provide the care and nurturing that is so critical for a child's optimal development. Attention was first drawn to the needs of HIV and/or drug affected children by publicity focused on babies who were "boarding" or "abandoned" in hospitals. Such children represented the tip of the iceberg but served to draw attention to the much larger number of children whose parents were unable to provide the stable care and nurturance necessary to ensure their safety and well-being and for whom there was a lack of alternative options for care.

#### The cocaine epidemic

Cocaine abuse emerged as a major epidemic in the early 1980s as the drug became more widely available and less expensive. At the same time, "crack," a more purified and more addictive form of the drug appeared on the street. Within a ten-year period between 1980 and 1990, estimates of the number of heavy users of cocaine increased two and half fold, from approximately 700,000 nationally to 1,750,000.<sup>1</sup> Rates of cocaine use among pregnant women receiving care in prenatal clinics located in metropolitan areas ranged between 10% and 20%.

Use of cocaine during pregnancy may frequently result in babies being smaller and can cause babies to be born prematurely. Thus, there is an increased likelihood that these babies will have medical complications following birth and will require lengthy hospitalizations, often with very costly treatment in intensive care units. These problems were exacerbated by difficulties in finding homes for children whose parents were not able to provide appropriate care. For example, in a study conducted in New Haven, Connecticut between 1989 and 1991, 23% of the babies born to cocaine-using women were born prematurely, a rate four times higher than expected.<sup>2</sup> The average time they spent in the hospital was twice as long as other babies and more than half of this time was spent in an intensive care unit. The average cost of the hospital stay was \$ 6,194,

approximately three times the usual cost for a newborn infant. This was not just a localized phenomenon, but was occurring across the country, and in some places the statistics were much worse. In a national survey of 865 hospitals conducted in 1991, there were over 20,000 infants who were living in hospitals awaiting placement decisions, and 79% of these had been born to drug-using women.<sup>3</sup> These “boarder babies” spent an average of 46 days in hospital, but for only half of this time were there medical reasons for the children’s stays.

The cocaine epidemic was affecting the lives of children in other important ways. Perhaps most significant was the increasing rate of child abuse. For example, in one study almost 10% of young children born to cocaine-users were seen at a hospital because of abuse or neglect, and a quarter of the children had to be placed with someone other than their parents.<sup>4</sup> Nationally, the rate of foster care placements skyrocketed over a very short period: prior to 1986 there were about 270,000 children in foster care, but by 1990 this had risen to over 400,000.<sup>5</sup> Within just two years, between 1986 and 1988, the rate of cocaine use more than tripled in New York City, and along with this, reports of child abuse went up by 43%. There were grave concerns about the adequacy of care received by those children who remained with their parents.

The effects of parental cocaine use on children’s development has been less clear. While some studies have demonstrated that infants born to cocaine-using women respond differently to stimulation than do other infants, it now seems evident that cocaine exposure during pregnancy does not result in the severe abnormalities in children’s development and behavior that were initially feared. What is clear, however, is that these children may be handicapped by the circumstances in which they are growing up. In some cases, the parents’ inability to respond appropriately and provide the nurturing and stimulation that children need will ensure that they fail to reach their full potential.

### The HIV epidemic

There have been major changes in the AIDS epidemic since the disease was first described almost two decades ago. In the early years, only 7% of persons with AIDS were women. This is in sharp contrast to now, when approximately one-third of all new cases of HIV infection are in women, and the majority of these are mothers. The epidemic is increasingly affecting poor, minority populations, and since 1996, African-Americans have outnumbered whites in new AIDS diagnoses, despite the fact that African-Americans only represent 13% of the country’s population. There was a major turning point in the epidemic in 1996 when the introduction of new therapies led to a dramatic decrease in the number of people progressing to AIDS and dying from the disease. Such figures, however, have resulted in a premature sense of relief due to an incorrect belief that the epidemic is slowing down. In fact, the number of people becoming infected with HIV each year remains relatively stable and is even going up slightly among women.

Fortunately, the improved health of parents infected with HIV has meant that the number of children orphaned by AIDS has not been increasing at the dramatic rate predicted in 1992.<sup>6</sup> However, the number of parents living with the disease continues to rise, thus there is an increasing number of children affected by the disease. Parents still have to cope with maintaining their own health, while the fear of death always remains. They also have to cope with the many

issues surrounding the disease, perhaps the most important of which is the emotional exile that they often experience because of the stigma associated with HIV/AIDS. Parents often are unable to turn to their families or friends for help and must face the consequences of their disease alone, silently grieving. This silence and isolation can have serious consequences for children. A parent's emotional state and ability to cope is of the utmost importance in promoting a child's healthy psychological development, and studies have shown that children of HIV-infected parents are more withdrawn and depressed and older children engage more frequently in the types of behaviors that may put them at risk of contracting HIV.<sup>7,8</sup>

If a parent does become ill, or even dies, it is important to ensure stability in care-giving for the child. Before the AIDS epidemic, most laws governing custody of children if their parents were to die presumed that there would be second parent who would continue caring for the child. A mother dying from AIDS, however, is most often single, or, in some cases, the child's father may have died before her. With support, parents can often focus better on the emotional needs of their children, and, as they approach death, parents can be helped to secure stability for their children and ensure that their children suffer as little as possible from their own tragedy. To assist in this there is a need for policies establishing "standby guardianship" that is more responsive to the needs of parents helping to ensure stability for the children.

#### SAVING CHILDREN: THE ABANDONED INFANTS ASSISTANCE PROGRAMS

The Abandoned Infants Assistance (AIA) Act (P.L. 100-505) of 1988 provided funding to prevent the abandonment of children through the provision of services to children and families affected by HIV/AIDS and substance abuse. It is worth noting that this Act was initiated at a time when it was considered by many that crack-cocaine users were untreatable and should not care for their own children, and that people with AIDS were not worth treating. Thus, in some respects, it was a bold move for Congress to pass a law that enabled communities to address the needs of segments of the population that were considered to be beyond help. The law has subsequently been re-authorized in 1991 and 1996, and presently funds 34 demonstration programs in 18 states and the District of Columbia. In addition, a National Resource Center provides training, technical assistance, information and resources, and supports a network among the programs. The overriding goals of the AIA programs are to prevent the abandonment of children through the provision of services to families to promote stability in the care of children, and to ensure their safety and well-being. The program is administered by the Children's Bureau, Administration on Children, Youth and Families, Department of Health and Human Services.

The programs have been tailored to address the specific needs at each site, and thus there is diversity in the designs of the programs. However, they share a common thread in promoting interagency collaboration and networking in their communities to achieve their goals. Such collaborations often require forming alliances between different organizations that have seldom worked together, such as substance abuse treatment centers, child welfare agencies and health care facilities. Through comprehensive home-based and on-site services, case management, and peer support, AIA programs address the complex needs of families and reduce costly duplication of services.

There is a recognition that parents most often want to do what is best for their children, despite their own problems with drugs or HIV disease, and that, with added support in addressing their problems, they can better ensure success for their children. When parents are unable to provide their children with the appropriate care, the programs often support relatives in maintaining the care of the child within the family. AIA programs have played an important role in gathering information used in the development of new policies governing the custody of children in the event of the parent’s illness and death and have been instrumental in helping sick parents facing their own deaths with the legal procedures required to ensure their children’s stability.

To date, the AIA programs have served over 10,000 individuals and each year more than one thousand new families enter the programs. Approximately 81% of the children served by the programs are children of color; 59% are African-American and 18% are Hispanic.<sup>9</sup> In four out of five families, the mother is a single parent, and 58% of mothers failed to graduate from high school (See Table). Most of the mothers used drugs during pregnancy and almost a quarter of them were HIV-infected. Their prior histories of trauma and hardship are striking and speak to the high levels of stress and dysfunction that they bring to the task of being parents. Over a quarter of the women reported having been physically abused in their own childhood and 21% reported having been sexually abused, 23% had a history of a psychiatric illness, and over a third had already had a child removed from their custody prior to enrollment in an AIA program.

Table: Characteristics of mothers enrolled in AIA programs

Characteristic	Proportion
Single	80%
Less than a high school education	58%
On Medicaid	57%
Substance use during pregnancy	86%
HIV positive	23%
History of physical abuse	27%
History of sexual abuse	21%
History of psychiatric illness	23%
Previous child removed	34%

## PROGRAM SUCCESSES

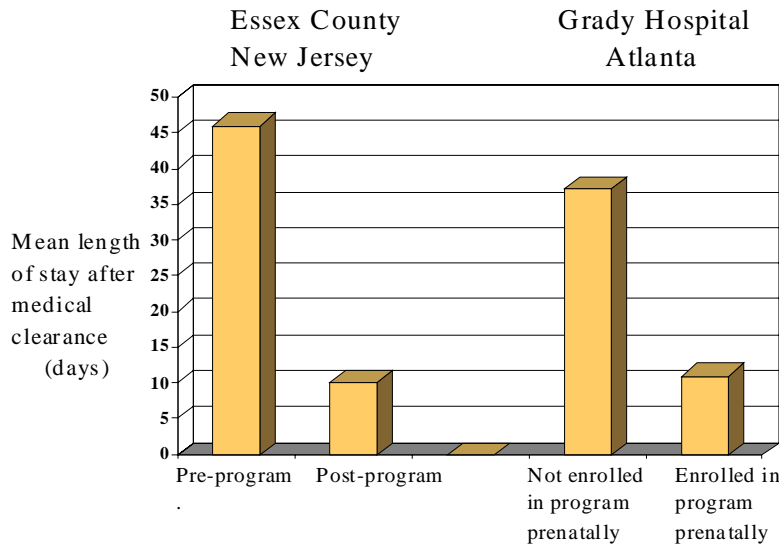
While the thousands of families served by AIA programs across the country provide a measure of the national impact of the AIA Act over the last decade, results obtained from individual programs help illustrate the degree to which families and children have been helped by these programs and the extent to which the goals of the Act have been achieved.

What has happened to the boarder babies?

There has been tremendous progress in addressing the problem of boarder babies. National surveys of hospitals conducted in 1991 and 1998 demonstrated that the average duration for boarder babies staying in the hospital declined from 46 days to 32 days.<sup>3</sup> Importantly, the period that the babies needed to be in the hospital for medical reasons did not change, but the period that children remained in the hospital following medical clearance declined by 59%, from 22 days in 1991 to 9 days in 1998. Significantly, the average length of stay beyond medical clearance for babies enrolled in the AIA programs in 1998 was only two days!<sup>9</sup> The contribution of individual AIA programs to this dramatic change is evident in the data provided by some of the programs. For example, the New Start Project in Newark, New Jersey served 1,914 children and families over a three-year period and reduced the average length of hospitalization after medical clearance by 77%, from an average of 45 days to ten days<sup>10</sup> (Figure 1). In the year before Project Prevent was started in Atlanta, there had been 52 babies boarding in Grady Hospital for a total of 1,002 days.<sup>11</sup>

Figure 1

Effect of programs on reducing length of stay of boarder babies



Sources: New Start Project, New Jersey. Report 2000; Project Prevent, Atlanta, Georgia. Report 2000

Following introduction of the program, the number of boarder babies dropped to approximately 30 each year. An important finding was that women who enrolled in the Atlanta program when they were still pregnant and received services before giving birth had much better outcomes than women who entered the program only after their children were born. The babies of those who entered the program early, boarded in the hospital for an average of 11 days, whereas the length of boarding for those who entered late averaged 37 days -- more than three times greater. Between 1996 and 2000, the boarding cost for the 178 babies whose mothers had entered the program early was \$ 187,500, -- a substantial reduction from the staggering cost of almost two million dollars for the boarding of 270 infants whose mothers entered the program late. Obviously, women who enter the program early are more likely to get into substance abuse

treatment and stop using drugs, thus decreasing their risk of giving birth prematurely. In Atlanta, as in many of the projects, these results have been achieved through the creation of a network of services for women. More recently, the Atlanta project has added to their program a model transitional home for boarder babies to provide a much-needed alternative to costly hospital boarding of infants. Not only will this home substantially reduce the costs of caring for these children, but it will also provide them a more nurturing environment than the wards of a hospital.

#### Children are growing up in more stable environments

Perhaps the most difficult goal to achieve has been that of ensuring that the children are growing up in environments that are more stable and nurturing. While a goal of the AIA programs is to provide parents the support needed to care for their own children, this is not always possible. A parent's inability to deal with her addiction to drugs, or the death of a parent from AIDS, means that sometimes children need to be looked after by someone else. Recognizing the difficulties affecting the families being served, the programs have had relative success in maintaining children within their biologic families. For example, in 1998, almost three-quarters of the children were living in their biologic families at the time of terminating from the program -- 60% were living with their mothers compared to only 52% at entry into the program.<sup>9</sup> An additional 18% were living in foster care. It is difficult to know, however, how many more children might have been placed in foster care had it not been for the programs. Perhaps most significant is the fact that a third of all the mothers who were now caring for their children had previously had children removed from their care.

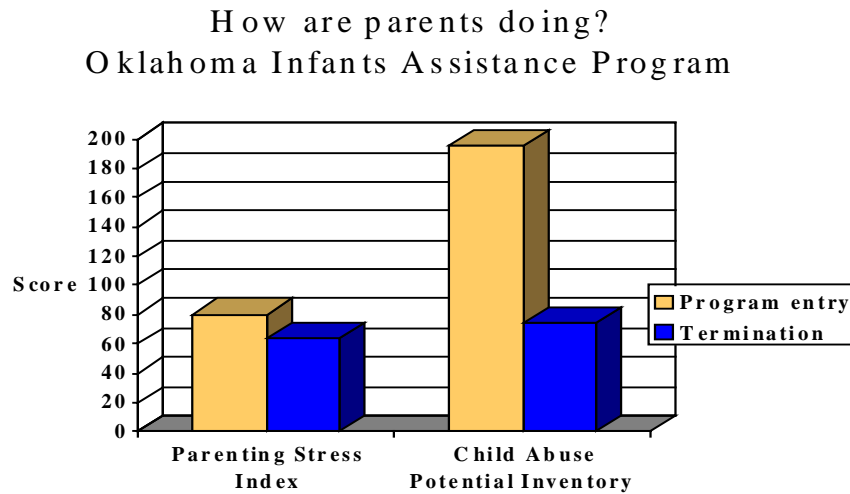
#### Parents are better able to care for their children

A parent's behavior and care can either promote or hinder a child's development. Thus, within the programs, there is an intensive focus on providing parents with the emotional support they need, attending to their mental health needs, ensuring their success in substance abuse treatment, addressing the stresses that are part of the everyday lives of those who live in poverty, and enabling them to be better parents. While programs have used different methods to assess such outcomes, the successes are evident. For example, in the TIES Program in Kansas City, Missouri, clients of the program were more successful in getting into drug treatment than were a comparison sample of women who were not in the program -- 92% of mothers attending the program enrolled in drug treatment, compared with only 73% of those who were not in the program<sup>12</sup> -- and in the Bienvenidos Program in Los Angeles, 84% of the clients who received drug treatment remained clean and sober at the time of termination from the program, a success rate that is substantially better than is seen nationally.<sup>13</sup> In contrast to other programs which have tried to serve this population, most of the AIA programs do not require the mothers to be drug free to participate. However, as part of their participation in an AIA program, many mothers entered and successfully completed drug treatment programs.

Women enrolled in the programs also report feeling more supported, less stressed, and psychologically improved. For example, the Philadelphia AIA program assessed the level of psychological distress among the women enrolled in their family-centered home visitation program and compared them to other women attending a clinic, and found that the women in the

program experienced a 33% drop in psychological distress compared with only 14% in the comparison group.<sup>14</sup> The Best Beginnings Program in New York City demonstrated that women in the program were less depressed six months after entry into the program, while women in a comparison group continued to have high rates of depression.<sup>15</sup> The Oklahoma Infants Assistance Program documented that mothers who completed the program reported a decrease in stress and a substantial reduction in their potential to abuse their children (Figure 2).<sup>16</sup> These documented successes mean that parents are feeling better about themselves and therefore are more able to successfully nurture their children.

Figure 2



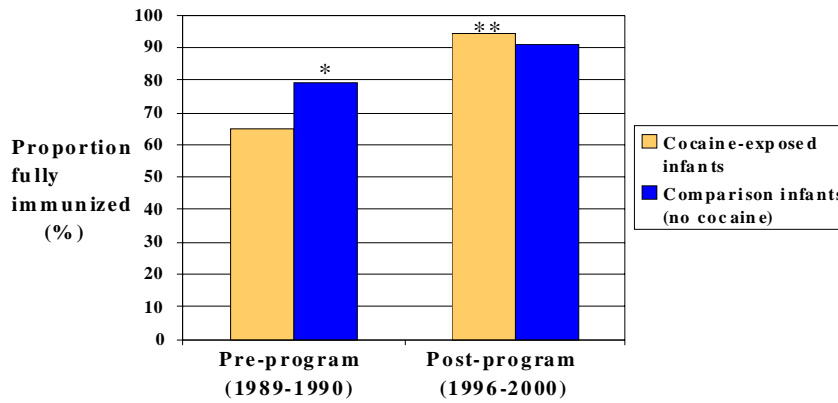
Source: Oklahoma Infants Assistance program, Oklahoma City, OK. Annual Report, 1999

### Improved care is affecting the lives of children

There are also indicators of how the quality of life has improved for children being served by the programs. One such measure is the fact that children are now receiving preventive health care that was previously lacking. For example, before the CIWI program (Coordinated Intervention for Women and Children) started in New Haven, Connecticut, only 65% of children born to cocaine-using mothers were completely immunized by one year of age, a level significantly lower than the rate of 79% among other children attending the same clinic.<sup>2</sup> In contrast, by 1999, 94% of children in the program were immunized (Figure 3).<sup>17</sup> Another important finding of the CIWI program is that the rate of abuse or neglect of these children was only a quarter of what it had been before the program started -- an earlier study documented that 8.6% of children of cocaine-using mothers were seen at a hospital after being abused or neglected,<sup>4</sup> whereas this occurred for only 2.3% of children in the program.

Figure 3

### Effect of CIWI program on immunization rates at age one year



Compared to cocaine-exposed infants pre-program: \* P<.05, \*\* P<.01

Source: CIWI program, New Haven, CT. Report 2000

Other more subtle benefits for children have been more difficult to document. Studies that have examined the effect of interventions similar to the AIA programs have only shown small improvements in the development of infants born to cocaine-using women, and these gains have not been sustained into the second year of life.<sup>18,19</sup> It is too early, however, to know what the longer-term effects of the AIA programs might be, although we can assume that assisting a mother to complete drug treatment and make dramatic changes in her lifestyle will have long-lasting benefits for her and her children, as long as she remains drug-free.

#### Policies to ensure the stability of children facing the loss of their parents

The AIA programs have played an instrumental role in helping to develop and put into practice new policies that ensure appropriate legal guardianship for children whose parents are ill or are dying from AIDS. Such initiatives provide children with as much permanency and stability as is possible as they endure this most horrendous of ordeals, and thus attempt to minimize the long-term psychological consequences for these children. At last count, 20 states had introduced laws supporting “standby guardianship”. These laws allow for a parent to name someone else, perhaps not even a relative, who can continue to care for the children at times when the parent is no longer able; thus, a parent can make sure that the children continue to be cared for by someone they know and are not, in their time of turmoil, placed in foster care with strangers. The task of planning guardianship is not an easy one for parents since often they do not understand the legal implications for their children, and addressing these issues means facing their own mortality. To help parents in this complicated task, a number of the AIA programs have developed initiatives linking legal services with social services and healthcare agencies. In Chicago, for example, a 1998 study documented that only 13% of HIV positive women had a legal plan for permanency for their children.<sup>20</sup> Since its initiation, Chicago’s Family Options Program has provided

permanency planning services for 379 children in 176 families, thus making a difference for the future of these children.

## FUTURE NEEDS AND DIRECTIONS

While the cocaine epidemic has slowed, it is far from over: in 1998 an estimated 1.8 million Americans were using cocaine, and 437,000 were using crack, a rate that has not changed in a decade. The poor continue to be most affected -- rates of cocaine use are almost four times higher for people who are unemployed than for those with jobs, and the rate of use among high school dropouts is almost three times the rate among those with a college degree. In addition, there are other drugs and alcohol that continue to endanger the lives of children; in total, there are 8.3 million children in this country living with a parent who is dependent on alcohol or in need of treatment for illicit drug use.<sup>21</sup>

The potential cost saving by treatment for alcohol and drug abuse is substantial; it is estimated, for example, that for every dollar put into treatment, there is a saving of seven dollars in reduced health care costs, increased employment, and reduced criminal behavior.<sup>22</sup> Such calculations, it should be noted, do not include the potential savings from decreasing the number of children being placed in foster care. Money spent on substance abuse treatment for mothers is estimated to save twice that amount in child welfare expenses.<sup>23</sup> These outcomes, however, require the linkage of treatment programs for HIV infected or substance-abusing women with a range of coordinated child and family-focused services as exemplified by the AIA programs.

While the AIA programs have demonstrated substantial successes in achieving the goals of the Abandoned Infants Assistance Act, there is a continuing need to build on these successes and expand the reach of the programs. As noted above, both the drug and HIV epidemics are changing and these changes often require changes in approach. For example, there is a resurgence in this country in the use of heroin and infants born to heroin-using women also spend long, costly periods of time in the hospital. Unlike cocaine-exposed children, however, these children spend additional time in hospital because they require medical management of their withdrawal from the drugs that they were exposed to prior to birth. A study done in New Haven, Connecticut showed that infants born to opiate-using women spent an average of 50 days in a hospital withdrawing from drugs at an average cost of \$ 52,000 per child.<sup>24</sup> Discharging these children from the hospital earlier, while ensuring their safety, will require a different approach. Services will need to incorporate intensive, home-based nursing and medical care with supportive services and substance abuse treatment.

There is also a need for the programs to use the knowledge and understanding that has been gained from working with these families to increase their successes and disseminate their expertise more widely. Program staff have learned a lot about how to engage families in services, but retention continues to be a problem when ongoing drug use interferes with clients' abilities to follow through. There continues to be a need to focus on ensuring stability of care for children. In the Maternal Lifestyles Study, a large multi-site study that examined outcomes for children born to cocaine-using women, one of the most important factors associated with poor

developmental outcomes was the number of times children had experienced changes of caretakers.<sup>25</sup>

There are another two important areas which, with greater emphasis, could substantially improve outcomes for mothers and their children. First, programs need to further examine ways in which women can be enrolled before they give birth. If a woman can successfully stop using alcohol or drugs during her pregnancy, she can possibly save her infant from the terrible consequences of exposure to these drugs, and, in the case of cocaine, from the danger of being born prematurely. The avoidance of costly hospitalizations of newborn infants -- whether because of prematurity, withdrawal from opiate exposure, or lack of appropriate, alternative care -- can more than defray the costs of such interventions. Second, programs need to focus more on helping women make choices about future pregnancies. Cocaine use, in particular, is associated with the failure of women to use contraception and with a high risk of repeated pregnancies. With support and attention to their multiple needs, such women may be more likely to use family planning services.

As with the unfounded decrease in concerns about drug use, there has been a false sense of optimism regarding the HIV epidemic. It is true that most HIV positive women are healthier than they were just few years ago; there are, however, just as many women becoming infected in this country each year, and these women cannot be assured of living long enough to see their children grow to adulthood. Assistance to HIV-infected women through the AIA programs not only ensures greater stability for their children, but also has the potential to help these women better address their own health care and maintain adherence to treatment. This is of particular importance if an HIV-infected woman is pregnant, in which case, medical care could prevent her from transmitting HIV to her child.

## CONCLUSIONS

Unquestionably, the demonstration programs initiated by the Abandoned Infants Assistance Act have had far-reaching effects on the lives of children that go well beyond solving the problem of boarder babies. The programs have done away with the old concepts of addressing the needs of mother and child separately, and instead, have developed unique models of care that provide coordinated, family-focused services that provide an array of services from health care to parenting support to legal services. The success of these demonstration projects speaks to a need to expand such services so that a greater number of children can be served. The models of care developed as demonstration programs by AIA sites, have proven to be effective treatment modalities and are now ready to be fully integrated into the existing health, mental health, and child welfare services, and substance abuse treatment system throughout the country.

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