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Barriers in Permanency Planning for Medically Fragile Children: Drug Affected Children and HIV Infected Children

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ABSTRACT: This article discusses the problems of medically fragile children, drug affected and/or HIV infected. Passage of the Adoption Assistance and Child Welfare Act of 1980 markedly increased the number of these children in foster care. The specific barriers to permanency planning for this group of children are discussed and include interviews with staff people, review of the literature and integration of material from pilot studies of families fostering and adopting children with HIV.

The passage of P.L. 96-272, the Adoption Assistance and Child Welfare Act of 1980, established a national policy affecting permanency initiatives for children in the foster care system and those at risk of entrance into the Child Welfare System. The legislation emphasized, in order of preference, preservation of the family at risk of disintegration, reunification of children with the biological family if children are in out-of-home care, promotion of adoption if reunification cannot be achieved, guardianship, and long-term foster care. Child welfare service providers were legally mandated to provide effective and timely permanency planning of these options. The passage of this legislation had particular relevance for children with special needs. The

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term "special needs" has been defined to include older children, adolescents, handicapped children, sibling groups, children with emotional and behavioral problems, and children of minority or biracial heritage. However, it was developed before two of the major epidemics to affect child welfare were evident: the HIV and drug (specifically crack cocaine) epidemics. Since passage of the legislation, this emerging population of special needs children has entered and dramatically affected the child welfare system. The recent increase in the number of children in foster care is attributed to these children, particularly the drug affected child (Barth, 1991). These two groups of children share common issues, as well as unique problems, which serve as barriers in the preservation of or reunification with their biological families. In addition, these two groups of children also present unique challenges to social service providers in the use of foster care and adoption in the permanency planning process.

This article focuses on specific barriers to permanency planning for drug affected and HIV infected children. Several approaches were used to identify barriers to family preservation, family reunification, foster care and adoption. They include the following: a review of the literature; interviews with staff associated with the Maryland Department of Human Resources' demonstration project entitled "A Family-Centered Transagency Model for Children with AIDS, HIV Infection, or Drug Exposure"; and integration of material from pilot studies of families fostering and adopting children with HIV (Groze, Haines-Simeon, & McMillen, 1992; Groze, McMillen, & Haines-Simeon, 1993).

The Scope of the Problem

Drug Affected Children

Research estimates of the number of infants born with exposure to illegal drugs each year range from 30,000 (Besharov, 1989) to 375,000 (Schneider, Griffith & Chasnoff, 1989), with 150,000 probably being the best estimate (Gomly & Shiono, 1991). Due to a lack of consistent screening and testing within the health care system, accurate counts of the total problem are still unavailable. In one study (General Accounting Office, 1990) it was found that the level of rigor in detection procedures determined the level of detection. For example, the detection rate of drug exposed infants in hospitals with rigorous detection

procedures was three to five times greater than in those hospitals with less rigorous methods. This has resulted in only a vague understanding of the scope of the problem.

Estimates of drug affected children entering or at-risk of entering the child welfare system are no better. Drug exposed children enter the foster care program at different stages. For example, not all drug affected babies enter out-of-home placement at birth. In a GAO (1990) study of 10 hospitals, an estimated 1,200 of the 4,000 drug-exposed infants (30%) born in 1989 were placed in foster care at birth. In New York City, between 1984 and 1989 the number of infants entering foster care at birth quintupled. By 1989, 4.5% of all births in New York City were followed shortly by a foster care placement (Wulczyn, in press).

Though only a modest proportion of drug exposed children enter the child welfare system at birth, those discharged from the hospital to drug abusing parents may later enter the child welfare system due to the chaotic and dangerous home environment. Officials in New York state estimate that 75 percent of foster care children come from alleged drug abusing (including alcohol abuse) families (CWLA, 1990). Nationally, it is estimated that 80% of drug-exposed children declared "dependent" in 1989 received out-of-home placements (Feig, 1990). Other estimates indicate that 30% to 50% of drug exposed children enter into foster care (FOCUS, 1990).

Some drug-exposed children carry a legacy of health and developmental issues, with short and long term results. The medical effects of drug exposure on the child vary with the type of drug used and frequency of usage by the mother. Drug-exposed infants may suffer significant medical problems. They may have difficulty in psychomotor development (Chasnoff, Burns, Burns, & Schnoll, 1986; Little, Anderson, Ervin, & Worthington-Roberts, 1989) as well as manifest difficulties in temperament, sleep, attachment behavior (Wachsman, Schuetz, Chan, & Wingert, 1989) and physical development (Smith, Coles, Lancaters, & Fernhoff, 1986; Kaye, Elkind, Goldberg, & Tytun, 1989). Long-term studies indicate that some drug-exposed children exhibit a range of problems such as poor motor skills, speech and language delays, short attention span, extreme apathy and/or aggressiveness, and difficulty in forming bonds with others (Cohen, Dinsmore, & Repella, 1989). However, the difficulties encountered by drug-exposed children are not uniform and generally not profound (Zuckerman, 1993). The difficulties generated by prenatal drug expo-

sure may require regular medical and neurobehavioral evaluations and lasting family interventions to meet the needs of the developing child.

HIV Infected Children

The growing number of HIV infected children threatens to strain an already burdened child welfare system. The first acknowledged case of pediatric AIDS occurred in 1982. This event marked the beginning of a rapid progression in the identification of this childhood illness. Through March 1993, the Centers for Disease Control (CDC) reported 4,480 cases of pediatric AIDS for children less than 13 years of age; this represents about 2% of the AIDS population (CDC, 1992). For every child with AIDS, 3 to 5 children are infected with the HIV virus (Novick, 1989; Oleske, 1987). Gwinn, Pappaioanou and George (1991) estimate that up to 80,000 women of child-bearing age may currently be infected with HIV. This means that 1,500 to 2,100 babies could be born with HIV in the U.S. each year. The means of transmission includes perinatal, sexual, and parenteral forms (Simonds & Rogers, 1992). The CDC (1992) indicates the following breakdown of transmission: 85% of pediatric AIDS transmissions were transmitted from mother to child, 13% resulted from exposure through transfusions or products associated with a hemophilia/coagulation disorder, and 2% were undetermined.

Pediatric AIDS cases are over-represented among ethnic and racial minority groups. In the U.S. White children represent 75% of the child population and only 21% (739) of pediatric AIDS cases; Hispanic children represent 10% of the child population and 25% (854) of AIDS cases; Black children represent 15% of the child population but 53% (1,844) of pediatric AIDS cases (Quinn, 1987; Hutchings, 1988; Select Committee, 1988; CDC, 1992).

HIV infected children carry a burden of health-related issues. One study observed that the birth height and weight of HIV infected children ranked in the 15th and 24th percentiles, respectively (Leeds, 1992). Head circumference, a measurement often associated with developmental risk, falls below the average with HIV infected children at the 20th percentile. Of these "two in every five HIV-infected children fall in the bottom five percent—a relative standing that can be equated with microcephaly" (Leeds, 1992, p.8). Several studies found the majority of children with HIV to evidence neuro and developmental abnormalities (Rubinstein, 1989; Johnson et al., 1989). By 1995, it

is estimated that HIV may become the largest infectious cause of mental retardation and encephalopathy in children under the age of 13.

The care needed by children with AIDS/HIV can include vigorous nutritional support, early hospitalization for treatment of possible infections, and monthly prophylactic therapy or treatment (Oleske, 1987; Rubinstein, 1987). Other procedures frequently used with these children includes medication regimens, tissue biopsy, CAT scan, gallium scan and esophagoscopy (Oleske, 1987). The major health problems include failure to thrive and chronic bacterial infections; children may also have chronic pneumonia, developmental delays and neurological abnormalities. Their medical care and prophylactic treatment require ongoing contact with a multitude of pediatric specialists.

The distinction between drug affected and AIDS/HIV infected children cannot be made clearly. There is significant overlap between these two groups of children. For example, Leeds (1992) indicates that 98 percent of the mothers in a pediatric HIV/AIDS study had used drugs while pregnant. While they are treated separately for heuristic purposes, the reader should keep in mind the overlap between the two populations. In addition, it is often difficult to assess which health problems are clearly caused by HIV versus those caused by poor prenatal care, poor diet, bad health habits in general, etc. of the mother. HIV infected mothers also have these risk factors that affect newborn health as well.

Barriers to Family Preservation and Family Reunification

Drug Affected Children

Barriers to family preservation and reunification for drug affected children and their families include the diminished functioning level of the addicted parent(s), the course of the addiction process, fear of legal prosecution, and inadequate treatment opportunities and programs.

The most obvious source of disruption to the family is the continued involvement of parents with illicit drug and alcohol abuse. Many barriers to family preservation are directly or indirectly related to the drug involvement of the family. The characteristics of drug affected mothers, as described by Chasnoff (1990), reveal the multitude of issues that complicate maintaining the preservation of a family:

> They (drug abusing mothers) are frequently described as having low self esteem, a poor self concept, and limited family support. They are less well educated, more frequently unemployed, with less stable housing than their nondrug-using counterparts. They come from dysfunctional, often chemically dependent families, and have a long history of violent or unhealthy relationships. They are more likely to have been victims of early sexual or physical abuse. They are less likely to receive prenatal care and are more likely to have multiple health problems. They usually possess poor parenting skills, and require a range of services from a variety of systems in addition to drug treatment (p.172).

Underlying this quagmire is the addictive process. Addiction is a circular process in which the individual progressively develops a fugue-like preoccupation with her/his substance of choice. This psychological dependency may lead to physical addiction, requiring formal substance abuse treatment. During the course of the addiction process, there is a diminished functioning level of the parent(s). Intrinsic to the process of addiction is the role of denial. The addicted parent will utilize denial as a means of minimizing and disassociating herself or himself from the impact and consequences of the addiction upon the entire family.

Interactions between mothers who abuse drugs and their infants are frequently impaired. A study of dyadic disturbances in cocaine-abusing mothers and their babies noted a lack of reciprocity and mutual enjoyment in their relationship. Mothers showed less social initiative and resourcefulness, and the babies had less positive affect than found in a standardized control group of mothers and infants (Burns, Chethik, Burns & Clark, 1991). Attentive, perceptive caregivers are needed for infants whose prenatal exposure to drugs may have created problems in their ability to regulate arousal and activity. Parents whose perceptions and behaviors are impaired by their own drug use will have difficulty responding in a manner that will help the infant to overcome these problems (Zuckerman, 1993). Also, children in substance abusing homes are at high risk for abuse and neglect (Sokal-Gutierrez, Baughn-Edmonds & Villarreal, 1993). The neglect which children and infants suffer at the hands of the addicted parent can be severe (DeBettencourt, 1990). This can include neglect of the child's basic needs (food, clothing, shelter), general neglect, violence, abandonment, and expending limited financial resources on obtaining drugs.

Child abuse is an indirect source of familial disruption. Child abuse cases attributed to drug dependence rose 72% from 1985 to 1988

(FOCUS, 1990), with 80% to 90% of child abuse and neglect cases involving parental substance abuse (Cohen et al., 1989; Besharov, 1989). In one study (Koppelman & Jones, 1989), parental substance abuse was a factor in 73% of child fatalities. In addition, Herskowitz (cited in Jones, McCullough & Dewoody, 1992) has observed that the younger the child, the higher the risk. An examination of records in Boston found that when the child was less than a year old, the involvement of parental substance abuse in child abuse cases rose to 89 percent.

Abuse of the child has legal ramifications. The fear of legal prosecution creates a high level of fear in the substance-abusing parent. Parents are afraid of legal prosecution for illicit drug involvement and are concerned about the potential of out-of-home placement of a child. For example, in Illinois it was estimated that over 50% of women in drug treatment programs lost custody of their children due to abuse or neglect prior to entering treatment (CWLA, 1990). The rates of reunification are unknown. However, the California Senate Office of Research reported in 1990 (cited in Barth, 1991) that drug involvement undermines the potential for reunification: ". . . most counties are finding that if the baby is not placed back with the mother almost immediately, the likelihood of that child ever being returned to that parent is quite low" (p. 2).

Another obstacle in permanency planning is related to the availability of treatment facilities. A high proportion of the addicts who seek treatment are turned away (CWLA, 1990). A study conducted by the National Association of State Alcohol and Drug Abuse Directors (cited in GAO, 1990) estimated that 280,000 pregnant women were in need of drug treatment, with less than 11 percent receiving care. Due to the tenuous nature of an addict's motivation in entering treatment, immediate availability is crucial. However, extensive waiting periods are common.

The barrier of treatment availability is compounded by programs refusing services to pregnant drug addicts or mothers with small children. For example, DeBettencourt (1990) reports that in New York City, over half of the programs refuse to treat pregnant women, 67 percent refuse to treat pregnant women on Medicaid, and 87 percent had no services for pregnant women on Medicaid who are addicted to crack or cocaine. Bowsher (cited in Jones et al., 1992) has noted that federal antidrug strategy has targeted less than 1 percent of funds for the treatment of women, and even less for pregnant women.

Related to the issue of access to treatment is the issue of child care.

Children may be involuntarily placed in foster placement prior to entering treatment. For women entering treatment who are not faced with an involuntary foster placement for their child, there are two options for the care of their children. Often, children are left in the care of drug-involved family or friends, or a child is voluntarily placed in temporary foster care. There are risks affecting reunification in both scenarios. In the former, a child could be taken from the home of the assigned caretaker while the mother is in treatment, and in the latter the mother could lose custody of her child if she violates her abstinence or does not follow her case plan.

Additional obstacles that impair the potential for family preservation or reunification are observable within the prevalent treatment program formats. Matching appropriate treatment with the needs of a client can be problematic. Most programs focus on the psychoactive substance use disorder and an addiction model of treatment, with very little or no consideration of accompanying psychiatric conditions or individual psychosocial factors. There is little or no family therapy (Westermeyer, 1991). In addition, there is growing momentum in restructuring alcohol and drug abuse treatment from inpatient facilities toward an outpatient orientation. As one clinician observed, ". . . the people we see coming into the system are more in need of habilitation, not rehabilitation, which lends itself frankly to longer term and more structured care" (CWLA, 1990, p.122).

Perhaps the most threatening aspect is that treatment programs do not address the greater resource needs of poor clients. If the larger environmental and long-term survival needs of the parents are not addressed, the lack of resources sets the parent up for additional drug usage when returning to the original home environment. If her child is involved with the social services delivery system, the reunification of child and parent is often determined by the parents' successful abstinence. Yet, in the final analysis, a lack of resources will almost ensure a return to drug involvement, leading ultimately to a return placement of the child into the foster care system.

The limitation in treatment access and of agency programs is compounded by service agency providers' attitudes toward the recovery process, and their understanding of addiction in general. The systemic interpretation and response to addiction tends to be punitive in nature. For example, a relapse is interpreted as a conscious failure on the part of the parent to respond to treatment. Misunderstood is that such a relapse is a singular event in the long and difficult process of recovery.

Additional impediments for permanency with the birth family are the lack of specialized services and the accessibility of existing services. There exists a lack of family-based services to provide continuity between services delivered to parent and child, on the one hand, and the reality of the home environment on the other hand. The gulf between the services provided and the needs of the family in the home environment is stark and vacuous. In addition, the resources that are available are often not coordinated so as to avoid duplication. Even the logistics of transportation from one agency site to another can be discouraging, particularly when motivation is strained and sources of childcare are nonexistent.

In addition to a family-based approach, there is increased recognition of the need for community-based strategies in social services. Many social problems are clustered in specific areas. The ecological niche promoting the spread of substance abuse problems in the inner cities was created in the sixties and seventies as the middle classes emigrated from inner city communities, leaving only the poorest people behind (Inclan & Ferran, 1990; Koppelman & Jones, 1989). A systemic solution to the substance abuse epidemic must include a community-based perspective (Walker & Small, 1991). A community-based perspective involves working with the community to solve its problems, building on the strengths and resources that exist. It also involves increasing resources to the community by locating services and programs within specific communities/neighborhoods.

While there are many problems, there are several programs that can serve as model treatment programs. The Edna McConnell Clark Foundation (cited in CWLA, 1990) reported on one successful program, highlighting the degree of resources needed. Michigan's Families First program has a significant success level of family intactness. Eighty-nine percent of the families served in Michigan were still intact six months after services were completed. The resources utilized included:

> . . . the ability of the caseworker to access appropriate drug treatment for mothers (including child care); the ability to relocate families out of drug-infested neighborhoods (almost half of the families have received this service); the ability to access "flexible money" (as much as $1,500 per family); and the very low caseload (two to three families per worker), that assures the ability to provide intensive services (CWLA, 1990, pp. 184-185).

HIV Infected Children

The obstacles undermining family preservation and unification for HIV infected families are also significant. The barriers are similar to those for drug affected children, with the difference only being those created by the diagnosis. Specific issues related to HIV, however, make certain barriers more unique. The population of HIV infected children tends to be more vulnerable, in general, with additional existing economic and psychosocial stressors. The factors which influence preservation of biological families where HIV is a problem include the difficulties internal and external to the family system, issues associated with a deadly disease, and obstacles from the service delivery system.

Economic and psychosocial problems are major threats to the preservation of a family with HIV. Families with HIV members tend to be in lower economic categories, usually living in impoverished conditions. The experience of these families includes poorly developed social networks, a lack of psychological support, and often a history of depression, stigma and rejection. The already weak coping capacities of a vulnerable family are threatened with further disorganization and crisis by the chronic illness (Septimus, 1990).

The limited economic resources for these families are striking. Prior to any diagnosis of HIV infection, the basic needs of the family were often not met (i.e., housing, food, medical and emotional needs). As an indication of economic problems, according to the Pediatric HIV/AIDS Health Care Demonstration Project (undated report), one-third of mothers report a change of address since the birth of their child, the majority making two to four moves during the course of one year. Showing the relatedness of economic and psychosocial issues, Kazak (1989) studied the total health care costs for 40 children with AIDS. Findings indicated that 20% of the total health costs were related to the children's social circumstances; this was attributed to the high rate of homelessness for the child's family.

The psychosocial factors extend beyond issues of economics. Economic problems are often connected to parental alcohol or other drug abuse, interfering with the ability of parents to meet the needs of their children. As an indication of the relatedness of HIV and substance abuse, Kemper and Forsyth (1988) in their study of 34 children with HIV infection observed that 97% of the children had a parent who was an intravenous drug abuser.

The disease itself is an obstacle affecting family preservation. The

unpredictability of the disease produces extreme levels of stress. The uncertainties of the illness are so profound that the medical, financial, and emotional factors can be overwhelming issues. In fact, it has been observed that the impact upon the family will be long term, if not permanent (Septimus, 1990):

> A child diagnosed with HIV infection causes chaos, disrupts family balance, and upsets the operational structure of the family at almost all levels. Families find themselves challenged with multiple powerful stresses by the medical diagnosis, the treatment, the course of the disease, and the possible outcome of life or death. Although the initial shock, anger, and chaos occur with the diagnosis, parents experience continuous fear, disbelief, anxiety, pain, stress, and feelings of being on an emotional roller coaster . . . Many clients report that the effect of the child's disease on the family continues throughout life, even after the death of the child. Recurring themes include social isolation, depression and grief, guilt, and disruption and disorientation. (pp. 94-95)

The familial response to a diagnosis of HIV infection can impede or enhance family preservation. A negative response may be fueled by fear of social and extended familial reprisal. This fear may preclude or handicap involvement with a particular service. Whereas HIV diagnosis may fast-track a family into services available, the fear for some families may prohibit participation in that service. Accessing services is desirable, as service delivery could reduce the traumatic disintegration of a family reacting to the trauma. However, it must be noted that the presence of services is not a panacea. Family integrity can be threatened and violated from boundary violation by service providers. In addition, HIV infected families with drug involved parents would tend to avoid any agency contact. Self disclosure of a substance abuse problem could lead to legal prosecution or the out-of-home placement of a child in foster care, decreasing the likelihood of service involvement.

The definitive barrier to reunification for a child with HIV is the death of a parent(s), although parental incapacity can also thwart reunification. In a New York study, 63 percent of the children do not live with their biological parents because the parents are either too sick or too dysfunctional to provide appropriate and necessary care for the child (Rudigier, Crocker, & Cohen, 1990). In such circumstances, the extended family may serve as a viable option of placement, which adheres to the intent of a definition of reunification.

Barriers to family reunification are also related to agency policy and resource allocation. The increased medical expenses for the HIV

infected member are an enormous economic burden for these families. Unfortunately, the service delivery systems created to assist such families are often impediments to their own mission. Policies that determine eligibility often threaten the integrity of the family unit. For example, in order to qualify for medical assistance, some families must place their child in foster care. The solution was a double-bind with diminishing returns: the child may gain medical assistance after being turned over to foster care, yet the mother may suffer an over-all decrease in other forms of financial assistance, such as SSI eligibility, which threaten efforts at reunification.

Foster Care

Drug Affected Children

Foster families serve an important function in the permanency planning of all children; however, there are unique aspects to fostering drug exposed and HIV infected children. One issue that transcends the discussion of these medically fragile children is the lack of available foster homes in general. The growing crisis in the child welfare system in general is attributed to the growing needs of drug exposed children (Barth, 1991; CWLA, 1990; Feig, 1990; Jones et al., 1992). The GAO study (1990) specifies this growth:

> In three cities that are required by state law to refer drug-exposed infants to child welfare authorities the number of infants referred during recent years has increased dramatically. In New York, referrals increased by 268 percent over the 4-year period 1986 to 1989. For approximately the same period, referrals in Los Angeles increased by 342 percent and in Chicago, by 1,735 percent (p.30).

The relationship between entrance into foster care and prenatal drug exposure is clear. A study of newborns suggested that 26 to 58 percent of drug-exposed infants receive foster care placement compared to 1 to 2 percent of those infants whose mothers showed no evidence of drug use (GAO, 1990). What is less clear at this time is the proportion of those placements that could have been prevented.

Concomitant to this growing population of children needing foster care is a growing crisis in the number of foster families. It is estimated that the number of foster parents has fallen by 34 percent in recent years (CWLA, 1992). Issues of difficulty in providing care for

the children are related to foster families' concerns about the extent of developmental and neurological damage to the drug affected child. This is directly related to the impact of the child upon the foster family and the foster family's ability to provide services equivalent to the child's needs.

Compounding these concerns of foster families are their experiences of difficulty with the larger child welfare system. In a pilot study of Maryland foster families (Groze et al., 1993), 75% of the study sample identified difficulties with the Department of Social Services. Issues raised included a failure in providing services intended to meet the needs of the child, and the high demands upon families providing foster care. The success of reunification, whether a return to the biological family or adoption, is jeopardized if the system does not provide the necessary support for its own foster families.

The limited, and often diminishing resources, of the child welfare system are well known. This clearly diminishes the number and effectiveness of foster care providers. Additional issues related to resources which discourage foster parents include insufficient in-home supports and low boarding rates (CWLA, 1992).

Limited resources of the child welfare system also affect the child prior to arrival into the foster care system. In the CWLA (1992) study of hospitals with boarder babies, 90% of the hospitals cited the child welfare system as a major contributor to the boarder baby problem. Because of a shortage of trained foster parents, understaffed agencies with overwhelming caseloads and no weekend services, medically cleared infants were often forced to extend their stay at hospitals. The result is ironic: a lack of resources maintains a hospital stay that can cost up to $800 a day, expending additionally scarce resources (GAO, 1990).

The growing demand placed on the child welfare system is daunting, with effective solutions elusive. In response to the resource crisis of the child welfare system, the concept of institutional care has reemerged as a possible solution. In the arguments of its proponents, this is justified by the apparent "success" of other countries using such arrangements for abandoned babies and drug-exposed children (OSAP, 1992). While such an arrangement of congregate care could be perceived as a viable option, ultimately, it would primarily serve institutional needs at great fiscal cost. Yet, even that is not assured. These settings often have monthly costs that exceed foster care by 10 times and treatment foster care by three times. Further, initial placement in a group residence reduces the likelihood of a timely adoption

and does nothing to speed reunification (Barth, Courtney, Berrick, & Albert, in press). In addition, the developmental tasks of bonding and attachment of infants and children cannot be achieved within an institutional setting, regardless of the best intentions of a well-trained staff.

HIV Children

As the needs of HIV infected children become more prominent, the role of foster care as an option for permanency planning will increase. Therefore, it is imperative that state child welfare systems be able to meet the demands. The estimates of children entering, or at-risk of entering, the child welfare system as a result of the AIDS epidemic is uncertain. Hopkins (1989) suggests that 55% to 60% of children with HIV infection enter foster care. Other estimates indicate that approximately 25% to 33% of infants born with AIDS or HIV will enter substitute care (Tourse & Gundersen, 1988; Melina, 1987; Boland, Evans, Connor, & Oleske, 1988). Uncertainty of the number of HIV infected children within the foster care system is also related to the lack of consistent testing of children (Emery, Anderson, & Annin, 1992) as well as issues related to the difficulty in diagnosing HIV in infants (McMillen & Groze, 1991).

Issues related to HIV infected children parallel those of the drug affected child. In addition to the already stated issues, others remain for the foster parents providing care for the HIV child. There are concerns over the impact upon the household in raising a child who may die in their midst. Given the volatility of the disease in the current social milieu, there exists the potential for social and extended family recrimination. An additional issue is that many foster parents have experienced struggles with child welfare service providers in getting the needs of the child met (Groze et al., 1993). Finally, the lack of information about a child at the time of foster placement as well as the burdens placed on families to locate routine medical providers who will care for a child with HIV discourage caregivers.

Adoption

Drug Affected Children

The foster care system was designed as a temporary answer to familial difficulties. The goal of foster care is, whenever possible, to reunite

families with children. When this cannot happen in a timely manner, the most permanent home is an adoptive home. Achieving the goal of adoption is complicated when dealing with drug affected and HIV infected children. There are significant barriers to adoption for the population of drug affected children. The most evident is the prospective parents' concern about the long-term developmental, neurological and behavioral issues with regard to the child. Specifically, what will be the ability of the family to provide the necessary resources for the child? What will be the demands of the child upon the adopting family? The lack of available information about drug-exposed children and journalistic horror stories about the difficulties of caring for them discourage prospective adoptive parents (Blakeslee, 1990). Often the developmental background and other associated issues of drug-exposed children are not definitive and their future is certainly unclear. Although the GAO (1990) cites early findings on drug-exposed children that raise concerns over the ability of adoptive parents to meet long-term needs of these children, the evidence is mounting that adopting drug-exposed children is not substantially different than adopting other children (Barth, 1991). Parents who adopted children through public agencies recently reported that they had more certainty about their child's drug-related history than parents who adopted children independently (Barth, 1991). Further, for years after the adoption, they were equally or more satisfied with their experiences of adoption and their closeness to the adopted child than were other adoptive parents (Barth, Needell, & Berry, 1993).

HIV Children

Regarding the child with or at-risk of HIV, the goal of returning a child to the birth family becomes particularly problematic if the mother has HIV. Initially, many of the mothers giving birth to children with HIV infection appear to be well. Over time, mothers become symptomatic, and some die (Boland, 1988; Gurdin, 1991). When a child cannot be returned to the home or to the home of the extended family, adoption is considered to provide the most permanent home.

There is uncertainty of the rate at which children with HIV/AIDS are entering adoption as a form of permanency planning. In the Children Awaiting Parents study (CAP, 1992), 16 states identified a total of 962 HIV children; 644 children were determined to be infected, 269 children antibody positive (and presumably asymptomatic) and 49 were classified undifferentiated or exact status unknown. Adoption

status of these children are as follows: 7% (44) of the infected children were free for adoption; 14% (37) of the antibody positive children were free for adoption; and 6% (3) of the undifferentiated children were free for adoption. The study was able to identify 102 children infected with HIV or antibody positive from 12 states having been adopted in the past three years (CAP, 1992). Many of these children were being adopted by their foster parents. The results from CAP suggest that adoption may not be given as a permanency plan for HIV infected children.

One aspect that is considered a major barrier for foster parents willing to adopt is the issue of subsidy rates (Emery et al., 1992). In a related study, families were fearful that the special funding available to them as foster parents could eventually be cut from state budgets if they became adoptive parents; they elected guardianship or long term foster care rather than risk the chance of being saddled with huge medical bills (Markese & Soule, 1992).

In the CAP (1992) study, states were asked if there was a foster care subsidy reduction for families if they choose to adopt. The study found the following: 5 states acknowledged a reduction if adoption was finalized; 4 states stated that adoption subsidies had to be lower than foster care subsidies; 9 states said there would be no reduction; and 14 states said it depended. The ambiguity and confusion surrounding the issue of subsidies is embodied within the comments from the 14 states:

> States said it depended on need and financial resources (means standard for state funded subsidy but not for IV-E children), case circumstances, county provider, eligibility for Adoption Assistance, adoption subsidy formula and individual negotiations with adoptive families, child's needs, if the auxiliary foster care rate is available after adoption; parents' income, child's eligibility for other funding resources (CAP, 1992, p.17).

Since then, California has passed legislation raising the adoption subsidy to the standard foster care rate even if the family has been receiving a foster care supplement because of the additional responsibilities of parenting a HIV-infected child or any other special needs child.

Additional issues identified included assuming the burden of responsibility for medical care of the child once adoption had been confirmed, the lack of family, social, and community support, and the length of time to get a case through the court. The length of time to

complete the adoption process can be problematic. This period of time can take up to several years, proving to be detrimental to a terminally ill child (Emery et al., 1992).

Families adopting children with HIV struggle with a broad range of experiences in terms of expectations and difficulties. A pilot study (Groze et al., 1992) of families adopting children with HIV highlights the many issues confronting these adoptive families. About one-third of the families reported that they were not given enough information about the child and over 40% did not feel that the services which were provided post-placement were helpful. One issue identified in the pilot study was related to the availability of resources. People were either surprised at the availability of resources or dismayed by the lack of them. In addition, the private system of medical care proved to create difficulty for some parents. One parent related the difficulty in finding a dentist and eye doctor for her child.

Another source of difficulty surfaced with a lack of receptivity to adoption on the part of adoption agencies—or state, court, or legal departments. As one parent noted, "Social workers' attitudes are often 'It's a poor dying kid, he's not going to live very long. What difference does it make?'"

The social arena of fear and uncertainty surrounding the issue of caring for children with HIV/AIDS was evidenced in the search for specific community services. One mother noted that she needed to return to part-time work to meet the added financial burdens due to the adoption. She abandoned her plans when she could not locate child care.

Implications

Highting barriers in the permanency planning process does not suggest that the legal mandate should be re-evaluated. Rather, it brings the issues that child welfare workers must struggle with to the forefront to open up a creative and meaningful dialogue on how to plan for HIV infected and drug affected children. Effective permanency planning for this new population of special needs children highlights the necessity for involvement with an entire spectrum of service providers. As the demand for services increases, the service providers and systems must forge new levels of inter-agency coordination and collaboration to meet the challenges (Woodruff & Sterzin, 1993; Ewing et al., 1993). With service provision divided between medical

personnel, child welfare workers, the courts, mental health workers, educators, the private sector and the public sector, there is a lack of shared knowledge that prevents an integrated continuum of care for these special needs children and their families. Future solutions must cross traditional lines of care, providing new and more effective means of meeting the needs of these and other special needs children (Smith, 1992). The health care system, the education system, the mental health system, the legal system, and the social services system must develop community-based models of collaboration, coordination and integration of services if we are to successfully preserve, strengthen and reunify families affected by HIV and drugs. Interventions guided by the principle of empowering families to move toward meeting their own needs and maintaining some sense of control will serve to enhance and develop strengths and abilities within family members (St. Clair, 1993; Schatz & Bane, 1991).

In addition, there is a need for new social work models of practice in family preservation and family reunification. Continued efforts should be expanded on "shared family care" arrangements in which HIV infected and drug affected or recovering parents and their children live with their children within a foster family home, supervised apartment, or residential treatment program (Barth, 1993; see also Nelson, 1992). Barth (1993) describes five living arrangements that enable the child and family to stay together while efforts to promote the parents' capacity to care for their children are pursued. These include:

> (1) child care homes (residential treatment programs for children) that also offer residence and treatment for their parents; (2) drug and alcohol treatment programs for adults that also offer treatment for children; (3) drug treatment programs for mothers and children; (4) residential programs expressly developed to offer care to pregnant and parenting mothers; and (5) foster homes that offer care of parent and child.

In addition, the traditional approaches to family preservation and family reunification may need to be reconceptualized in order to better accommodate the needs of families and children when a parent is dying. This is a different problem than has been the traditional domain of child welfare. As the percent of parents infected with HIV increases and as they move along the continuum towards terminal illness, there is a need to look at planning for preservation while at the same time planning for restructuring the family once the parent

becomes deceased or too incapacitated to care for the child or children. The notion of simultaneous options in permanency planning is unique and makes sense given the context and gravity of the problem with HIV.

The specific barriers to permanency planning identified in this article can also be used as a guide in the development of better child welfare policy. The importance of non-punitive and accessible prenatal care for high risk mothers is evident. Developing and expanding treatment programs for pregnant drug abusing women, without fear of criminal prosecution, is plain. Enlarging and supporting family preservation services for drug affected and HIV infected populations is critical. Exploring more equitable policies to encourage family reunification as well as funding the array of needed support services for biological, foster and adoptive families, is obvious.

On the last point, there is a need for federal leadership in the foster care payment and adoption subsidy systems that are in effect and vary from state-to-state. The foster care rate needs to be increased and the federal government needs to set a minimum adoption subsidy that is at the foster care rate. Adoption subsidies should not be reduced from the foster care rate, because they save the federal and state government in administrative costs once the child is adopted. States should be reimbursed for adoption subsidies at a higher rate than they are for AFCD-FC so that they are encouraged to move a child from foster care to adoption.

In addition, there is a critical need to combat the forces promoting group care for infants and toddlers. There is a need for federal leadership to limit to ninety days the participation of children younger than 6 years in group care. In California, some of these children are staying in group care for more than two years. In Maryland, 30 day crisis nurseries and shelters have become residential facilities with some children staying over a year. This is unacceptable and regressive, contrary to child development theory and research. The federal government already refuses to pay group care for adopted children placed out-of-home (that is as part of the subsidy)—they could certainly refuse to pay it for drug affected and HIV infected children.

In summary, many children affected by HIV and drugs will place additional burdens on a system currently strained and with diminishing resources, but there is every reason to expect and demand services that ensure that all children will live every day of their life in the care of a family that is passionately committed to their welfare.

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