CARETAKERS OF CHILDREN WITH HIV

IN EXTENDED AND FOSTER FAMILIES: THE FRENCH SITUATION

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Summary
In the context of HIV infection, the disappearance or inability to assume their parental role of one or both parents has focused attention on the generation of grandparents who are responsible for the offspring. It is only when they are unable or no longer able to do so that uncles or aunts, or even to a lesser extent friends, take on this role. The Social Services Departments step in as a last resort when there is no kinship option. However, the environmental vulnerability of these families and their psychosocial risk factors, which preceded the advent of HIV, are often the reason of the placement of children . Analysis of the interviews carried out on 36 family members and 20 professional foster families records their involvement on a day-to-day basis with the children, for the most part HIV- infected. It also highlights the constraints and difficulties involved in what is an extreme form of family solidarity, compared with the structured support of institutional care, which in turn has its own limitations.

Key words: HIV/Extended families/care/foster families

BACKGROUNDS
        The issue of the future of children, infected or not, whose parents are either suffering from AIDS or already deceased, has only recently been explored. Many of them suffer from disruption in caregiving. In the USA, foster care by adults other than the biological parents of the children affected by HIV infection is commonplace: 45% of children born to HIV- positive mothers resided with a primary caregiver who was not the biological parent (Caldwell et al. 1992). In France, in areas with high prevalence rates such as Paris and the Bouches-du-Rhône area, more than 10% of children born to seropositive mothers are raised by their extended families and approximately 15% are taken in by the Local Authority Social Services Departments (Dumaret et al., 1995a). A similar proportion of children living in the extended family, fostered or adopted was noted in Switzerland (Kunzel and Kind, 1992).
        Our research programme on Families and AIDS started in 1989 with the study of the environment of children born to HIV-positive mothers in Paris, the psychological impact within the families and the daily life of the parents (Dumaret et al. 1995b). In the second part of the programme (1994-98), the situation of children living with relatives or in foster care was analysed. Following a brief review of the literature on the impact of HIV infection on families and on the Local Authority Social Services Departments, the results of a quantitative study on

HIV-positive children placed by the Social Services in France will be firstly presented. Secondly, the specific features and those differentiating the experience of carers, both extended (EF) and foster families (FF), will be examined, based on two qualitative studies.

First of all, it is necessary, for foreign readers, to provide some information on the French structures specifically dealing with Child Welfare. The 21 regions of France are sub-divided into 95 *"départments"* –approximately equivalent to an English local authority. Each *département* takes responsibility for child welfare matters within its boundaries. Legal changes in 1983 brought about decentralisation and devolution of power from central government to the *"département"*. Currently each *"département"* is autonomous with regard to how its administration and financial decisions are made – it can for example decide on its own rate of allowances for foster carers. Some functions continue to be directly tied to central government, for example, with regard to children, Wards of the State. Thus, in each *"département"*, there exists side by side the functions for which there is devolved authority (controlled by 95 different general councils) and the functions for which, authority still lies with central government, the latter being organised identically in each of the 95 units.

In our Child Protection system, Local Authority Services Departments *("Aide Sociale à l'Enfance")* and Juvenile Protection *("Protection judiciaire de la Jeunesse")* are independent but there is a continuity between these departments. Legal and administrative interventions are complementary. The intervention of a judge is only required if a family's requests it or when there is an emergency or dangerous situation for a given child. It is only after a court order that families have to comply with these legal decisions, which very frequently are the final stage of administrative measures. A special branch of the Justice Services, the Juvenile Protection, deals with prevention of delinquency; it also plays a part in Child Welfare.

In 1999, 275,000 children and teenagers (1.5% of the French population under 21) benefited from a placement or from educational support while remaining in their families. Besides providing financial allowances, the function of the Social Services (child department) include preventive and educational support for the families (144,000 children in 1999) with temporary care and Wards (31,000 children), and placements committed by courts (112,000 children). Over three-quarters of them are carried out under the Social Services (child department) responsibility: they are reared in foster families or in institutions, and the others are placed directly by the judge: they are reared by extended families or other persons or by institutions. It is to be noted that financial support of all the placements by court orders is provided by the Social Services. Half of the children in care live in foster families, which are under control of foster agencies. In France, about fifteen percent of these agencies belong to the private sector. Private fostering agencies, which must be approved, are financially supported by the State.

INTRODUCTION

HIV and children: the cut-off point for comparison with other severe illnesses

The psychosocial repercussions of the HIV infection of the child on the family have been mainly described by professionals involved in the medical, psychological and social care of these families (Frierson et al., 1987; Taggart et al., 1992; Fair et al., 1995). Their descriptive approach to family situations and the stress family members experience highlights the particular characteristics of this disease, compared with other serious illnesses such as cancer which also affect children (Mattsson, 1972; Fanos, Wiener, 1994; Mellins, Ehrhardt, 1994). Family break-ups, the risk of losing other members of the family, the negative representation of the disease and the difficulties created by the social vulnerability of the majority of these families are the

most striking elements, all of which heavily impact on the physical and relational environment of the child.

In studies where the family is considered as an interactive system, HIV infection is no longer investigated simply in terms of sick individuals, but as a destabilising factor for the entire family system. From such a viewpoint, the impact of the child's disease on adaptation and functioning of the family depends on individual factors, such as the "ability to cope", and environmental factors, such as the socio-relational network and the social support system (Cobb, 1976; Kazak, Wilcox, 1984; Garmezy, 1985; Lesar et al., 1996). Recalling the determining link between socio-cultural background and the access or recourse to a social support system, authors report that families affected by HIV rarely seek for help and generally try to cope (Mellins, Ehrhardt, 1994; Schable et al., 1995). This is partly due to the fear of social stigmatisation that HIV infection represents, which in turn deprives families of potential individual and group support systems (Donati et al., 1996). Also, in the particular cases of families immigrated from Africa, it is due to defiance towards the Social Services (Matovu et al. 1998); in fact, they prefer to deal with private organisations (*Solidarité Enfants Sida, Dessine Moi Un Mouton...*).
As is the case in the United States, support groups are now being developed in France by voluntary organisations and in hospitals, which are doing their best to widen the groups to include grand-parents (Crandles et al., 1992; Chung, Magraw, 1992; Rufo, 1994).

Next-of-kin involvement in care
The definitive kinship care of a grandchild by grandparents is the norm for less than 2% of the French children; it corresponds to a family crisis situation (Attias-Donfut, Segalen, 1998). The rate of children brought up by their grand-parents is steadily increasing in the United States - between 4 and 13.5%- and is more a result of serious social breakdown than of major poverty of these families (Minkler, 1999). In a study carried out on children of African Americans drug addicts, the issues raised are the sharing of parental responsibilities in cases where the grandparents do not have legal custody of the child, and the serious disruption and modifications of their lifestyle and timetable (Burton, 1992; Jendrek, 1993). Although they take on a full parental role, they have no structural support to help them carry out this unexpected responsibility (Minkler et al., 1992). When the parents are AIDS patients, the lack of physical, emotional and material resources oblige them ask for help from their relatives so as to look after their children (Lesar, Maldonado, 1997). This is not an easy role for relatives to assume, as they themselves are generally also experiencing major social problems. Unlike foster families or unrelated caregivers, they receive no specific financial help from the State for bringing up these children (Paige, Johnson 1997). The setting up of such measures would ensure that families do not abandon their efforts and would ease the long term burn-out due to the care of such children, who are often orphans (Kelley, 1993; Levine, 1995).

Institutional care of children affected by HIV
HIV-infection of parents is rarely the only reason for children being in charge of the Social Services (child department): very few of them that have already lost their parents generally have other possibilities. However, they are for the most part the offspring of African parents who, before dying, have handed over their HIV-infected child to the French authorities to ensure that their child will benefit from high-standard medical care. For such sick parents, some of whom are still in their homeland, the delegation of the child is carried out by an immigrated relative who cannot personally look after him/her. Both immigrated families and staffs from the Local Authorities are facing numerous cultural, social and upbringing problems. For the vast majority, HIV-infection is only indirectly responsible for the handing over of the

child: pre-existing relational dysfunction added to the social and economic vulnerability of the parents are the main culprits (drug misuse, separation of the couple, lack of accommodation, psychiatric problems…). The reasons for admission in care are therefore similar to those of other children and refer back to the notion of "at risk children". The first two children born to a HIV-positive mother were admitted to the Local Authority Social Services Department in Paris in 1985. In 1989, the recruitment of the first foster carer for an infected child was a major event for institutions. From 1992-1993 onwards, the problem of the care of the other siblings one of whom was HIV-infected had to be dealt with. Most French local authorities, and particularly in the regions most concerned by AIDS, have gradually been developing training and information programmes for care professionals and those working with children in the health care and educational systems (Dumaret et al., 1995a). However, public health offices still did not know the number an proportion of children who will require care by someone other than a biological parent.

In the USA, according to Lesar and Maldonado (1997), an estimated 20%-40% of HIV-infected children now require foster or group-home placement. However, the level of care in child welfare services is still low: between 0.2 and 0.3% in 1991 (Felissa et al., 1994), with huge gaps based on local seroprevalence rates. In New York, Child Welfare Services have 618 infected children in care, representing 1.3% of all the children in care in the city (McNutt, 1994). In many states, the recruiting and training of foster families stresses confidentiality, the question of the separation and the death of the child, the importance of maintaining ties with the parents along with the medical and legal problems linked to the child's illness (Levine, 1996). Specialised psychological support networks and home help are organised in order to facilitate stability in what are always fragile care placements. The refusal of foster families to keep going the care of infected or ill children is linked to the fear of stigmatisation of the child and other family members, and, above all, the fear of the child's death (Felissa et al., 1994).

Psychological impact of the child's disease

While always difficult, speaking about the disease and death is particularly difficult in the case of HIV-infection. In the vast majority of cases, the women in charge of the infected children, be they the mothers, grandmothers or foster carers, generally only speak about the child's infection to their closest relatives (70% for Lesar et al., 1996). Keeping the secret from relatives is mainly done to spare the family unnecessary suffering, although reactions of fear and shunning have also been noted (Semple et al., 1993). Adults avoid explaining the infection to their infected children for as long as possible because they are afraid of trauma and rejection by the environment if the children talk about it to others. However, children are often much more aware of what is going on than their parents think, they internalise anxiety through their silence and avoidance (Dumaret, Donati, 1999). When one or both of their parents die, the importance of talking openly to the child about what happened has long been advised by clinicians, as otherwise he/she cannot even begin his own personal mourning process (Gourdon-Hanus et al., 1980). Landry-Dattée et al. (1993) stressed the importance of adult help in assisting children whose suffering is not always visible and for whom the primary anxiety is knowing who will look after them.

METHODS

The various care modalities of children affected by their parents' HIV/AIDS were studied in a two stage survey. Given the lack of data on the numbers of HIV-infected children in institutional care in France, a quantitative study allowed to investigate the magnitude of this phenomenon. A national survey was carried out via a postal questionnaire sent to the 95 Local

Authorities in 1997. A total of 92 out of the 95 *"departments"* in the mainland sent their data back. Simultaneously, a qualitative survey on caregivers (intra and extra family foster carers) was carried out from 1993 to 1997. It aimed to analyse how the care structure was installed, their functioning modalities. In order to cope with the new care situation, what the needs and resources were ? Semi-directive interviews were conducted with the extended families members (EF) bringing up one or several children, infected or not, and with foster families (FF) caring for HIV-positive children. Access to these persons was arranged by hospital services and institutional or voluntary organisation teams working with small children and AIDS in several regions. Interviews generally took place in people's homes: each had been looking after the child or children for at least six months.

In all, were interviewed:

i) 36 EFs: 22 grandparents (including one great grandmother), 2 great-aunts, 11 uncles and aunts (including 2 by marriage) and one friend family (the 2 great-aunts were studied with the group of grandparents and the friend family with the uncles and aunts).

ii) 20 FFs in several departments, 7 of which worked with a private foster agency.

The interviews focused on: i) the sense of their involvement for fostering and how they felt about their new parental role (EF), ii) the motivations of FFs, their relationship with the child and with the foster agency teams, iii) the consequences of the fostering on the whole family on a day-to-day basis, the difficulties experienced and the limitations of their commitment (EF, FF). The data concerning legal issues, practical and financial issues, the data on daily life and the way the caregivers cope with the illness have been published elsewhere (Dumaret, Donati 1999).

RESULTS

National census of HIV-infected children in the ASE care

In 1997, for France as a whole, 99,291 young people (0-18 years of age) were being cared for by the Social Services, including 56.4% by FF (SESI, 1998). Among them, 107 children and teenagers who were (or have been) in care, representing 1.1‰ of all the young people in placements were listed. This proportion was twice as high (2.7‰) in the Greater Paris area (Ile-de-France), which had the highest concentration with 46 HIV-infected children in care, followed by the Provence-Alpes-Côte d'Azur region (2.5‰), with 14 children in care. The 15 to 20% rate of under declaration was due to the fact that disabled children or children suffering from other diseases are not systematically registered by the Social Services (child department), although they are known individually to professional carers.

The main characteristics of these 107 young people are displayed in Table 1. At the time of the survey, more than half of the children were born in the last decade and 14% were teenagers. In general, the children were placed early (more than half before the age of 4). Early care placement was linked to the removal of a child at risk from its family, and less frequent for African children of sub-Saharan origin who were older when they arrived in care. Since they could not be looked after by the extended family, they "became" wards of the State, unless they had already lost both parents. In the early years of the infection, admissions were only for very young children (0-1 year) and the age range only began to widen from 1989 onwards.

The 57 FFs were mostly couples (89%), two thirds with dependent children of their own. Most of them have other children in care who are not HIV-infected: this is true of the 12 foster carers out of the 14 without biological children. The difficulty of finding foster carers or foster families in the geographical place where the child was born explained why many of them were recruited elsewhere. Thirty-seven percent were first time foster carers.

While almost half the children were in a foster family less than a year after their admission to the Social Services, a quarter had to wait between one and two years and another quarter waited three years and more. A long stay in institutions before arriving in a foster family is one of the characteristics of foster care in HIV cases. The average waiting period for a foster family has fallen steadily (improved information, networks…). Whatever the year of their admission, very young children always stay longer in institutions than older children (over a year on average). This is doubtless due to the determination of these institutions to keep these children geographically near their mothers, while the older children are generally orphans. Among the 21 young people who were no longer in care at the time of the survey, 13 had returned to their family, 7 had died from AIDS, one was a legal adult and data was unavailable for the remaining child.
Table 1

Analysis of kinship care and institutional carers
Care environment
Among the children born to HIV-infected mothers no longer living with their parents but not in care, two thirds were living with their grandparents, mainly those of French and North African origin, and a third with uncles and aunts, especially children of African and West Indian origin. It was generally the lineage of the first parent to die which was responsible for the children's education. As children were in general more orphans from their mothers (or their fathers were frequently lost for follow-up), it was more often the maternal lineage that took care of the children. The paternal lineage was more often involved for North African immigrant children as maternal family members were in the homeland.

Tables 2 and 3 display the socio-demographic data for EFs and FFs and the children at the time of the interview. A total of 52 children were in kinship care, half of whom were HIV-infected or already ill (27/52); this high percentage is due to the hospital recruiting of most of the EFs interviewed. In a third of instances, EFs were looking after sibling groups of at least two children; more than half the grandmothers (average age 55) were looking after children under two. In almost four out of ten cases, the grandmothers and aunts had no spouse. At the time of the survey, three-quarters of the children were over six and nine out of ten were orphans.

The 20 FFs interviewed were bringing up a total of 24 HIV-infected children. Three-quarters of the foster carers were between 40 and 55 when the child(ren) arrived. Three men were accepted as foster carers. Nine of the carers were already a FF before the arrival of the child and eleven were first time carers. These recent FFs often came from better off social backgrounds with professions in the social or psycho-educational fields. Their socio-cultural affinity with the Welfare foster care teams had a significant impact on their relationship with the institution.

The 24 children in FF care were generally reared with the children of their foster parents, or, less often, with other children in care that did not have HIV. Only 4 were in a family with another HIV-infected child. A significant number of the children came from other countries (14 children, mainly from sub-Saharan Africa).
Table 2

All the children (EF and FF) had experienced serious environmental breakdowns, especially those in care (series of stays in institutions for small children, temporary returns to their families…). One child in three had already experienced a failed care placement (discovery of their infection, relational difficulties…).
Table 3

Involvement of extended and foster families: similarities and differences
The "mission" of relatives
Grandparents are often the only family members that can take care of the child(ren). Their involvement is often a continuation of the assistance already extended to the sick parent, either as part of a tacit or more formal agreement. Some were rendered official during the last days of the illness: *"The judgement came a few days before she died and I was able to read the outcome to her and she died reassured, knowing the children would be looked after"* explained one grandmother speaking about her daughter. The less frequent instance of uncles or aunts taking on the responsibility generally resulted from the grandparent being unable to act as carer and is often an emergency solution (for African or Caribbean children).

The way carers, be grandparents or others, deal with their new role demonstrates that they are trying to sustain the memory of the parents alive. Replacing the mother was a taboo, especially when she was recently deceased, and there was no confusion between the position of grandmother and the role of the mother: *"I love my grand-daughter but I'm not trying to replace her mother. Having said that, I'm raising her as if she were my own"*. However, in cases where the ties between the drug addict son or daughter had become conflicting, some of the grandmothers assumed more of a role of parental substitute, taking the risk of discarding off the still living parents and sometimes, the grandparents from the other lineage. One grandmother, who had to give up raising her grandson and obey the decision taken by the judge to give him into the care of a maternal aunt commented: *"For me, it was really hard to see that my son was not assuming his responsibilities, it worried me. So I took on his role but it's true, it wasn't up to me to do so"*.

Motivations of foster families
When there is no kinship care solution, children are under the aegis of the Social Services, generally a family placement. As it was difficult to find foster families for HIV-positive children, the Local Authorities used the AIDS voluntary organisations network. This led to a greater diversity than usual and a series of "pioneer" or "atypical" caregivers, preparing the ground for the so-called "traditional" foster families. The motivations of the first families reflect a spiritual commitment and a determination *"to be with the child right to the end, even knowing he was going to die"*. Awareness of the "rejection" of HIV-infected children was a determining factor: *"In 87, all we knew was that it was fatal, contagious and that it affected homosexuals. And then I learnt from the media that it also affected children at birth and that those infants were being rejected. That I couldn't take"*. The second set of families approved for this type of fostering had already thought about fostering a deprived child and felt personally concerned, either emotionally or professionally, by AIDS: *"At the time, we had a niece with AIDS"* or *"I was already very involved in the AIDS support movement and the training given to doctors and nurses"*. Unlike the "pioneers", who felt the media claims involved them personally, these families travelled a long path of reflection before reaching their decision. Finally, for experienced FFs, the fostering decision was a continuation of their professional experience: more than a project, their decision reflected an acceptation of a proposition from a foster agency: *"After all, why not this child?"*

Along with the differences in terms of motivation, the new FFs were also different in terms of their relationship with the institution. In addition to the inevitable criticism every FF makes of institutional operating practices (lack of information on the child, scepticism about the effectiveness of the psychological follow-up...), the new FFs, recruited via voluntary AIDS organisations, also had other criticisms. As they often had high responsibility positions, they wanted more independence and were disturbed by the interventions of social workers which were often seen as being intrusive and a way of control: *"I don't think we were really cut out*

to be a foster family, which is why we did everything possible to get the adoption proceedings moving as quickly as possible, just to be rid of the institution". Their psycho-educative knowledge was on a par with that of the carers of the Social Services, which in turn made them judgmental and even led them to impinge on the institutional role, ignoring the boundaries set by the institution for any FF: *"I wanted Julie's mother to be involved again in the health of her daughter. So I asked her to make an appointment at the hospital... We also kept her up to date on Julie's fears by mail... whenever we felt that she was in a state to understand"* (woman psychologist and foster carer). Foster agencies do not normally function in this way: prerogatives are defined based on the role of each person: social worker, psychologist, foster family...

Day-to-day care issues

The arrival of the children in their new homes, even when the ground has been prepared, is the start of a new life for everyone in the family, with the exception of experienced foster carers. Grandparents have to set aside their own retirement projects or activities, lifestyle and interests in order to adapt to the needs of the child: *"Since they've been with us, we haven't been out once because we don't want to leave them alone. Before they arrived, we used to travel a lot." [grandparents looking after their two grandchildren].* Unlike uncles and aunts, these carers are out of sync with people of their own age-group. Grandparents have greater difficulties than aunts and uncles in bringing up the children; it is harder for them to communicate that the parent has died and, in the case of an infected child, disclose the child's diagnosis and manage the illness. Because there is a norm of family solidarity, the care given by extended families is often taken for granted. However, relatives may need a great deal of support as there are potentially many problems in caring for one or more orphans.

FFs are sometimes surprised by the violence of the child they have decided to foster: *"It was really hard at the beginning, I nearly sent her back!"* Behavioural and emotional dysfunctions, parental psychiatric pathologies, and multiple bereavement in the family are a heavy burden for these children, as illustrated by the severe psychological problems some of them display. Consequently, while FFs are generally younger than the grandparent group, the educational dimension is nonetheless hard for them. The capability to have contacts with the foster agency team enables them to understand, interpret and better cope with the difficult and sometimes pathological child's behaviour.

Most of these children have experienced environmental discontinuities linked to their parents instability and/or illness and are vulnerable to separation(s). Everything is done to ensure that they find themselves in a stable emotional environment. Their arrival in their extended family often takes place during the mourning period for the parents which relatives have to deal with in addition to taking care of the children. Children rarely arrive in such a context when they go to FFs, as the institutions have generally prepared their admission.

Day-to-day organisation is also different in concrete terms: the question of accommodation and financial resources, which is an integral element of the contract between a FF and the agency (accommodation must be of a certain standard, salary), is often still an issue for EFs. However, even when the economic cost of looking after the child has a negative impact on their budget, family members rarely mention it, as their commitment to the child is first and foremost a question of devotion. Financial resources are reduced, half of the families have below average income; there are strong discrepancies in the various regions among the funding provided by the Local Authorities.

Some of the grandmothers and aunts who were working full-time had to give up their jobs to look after the sick child, either temporarily or permanently. Availability is less a problem for foster carers whose professional life is focused on the child. In addition,

grandfathers and uncles seem less involved in domestic, maintenance and educational duties for the child than the husbands of newly approved foster carers, who are deeply committed to the foster project.

This new parental role upsets the positions and roles of all people involved. There are changes in the marital relationship in households headed by grandparents, aunts and uncles, and in sibling relationships too. This new role tends to invade the spouse sphere, especially for grandparents: *"My grand-daughter is everything to me. (...) I'm afraid my husband has had to take a backseat."* Tensions can emerge with other children in the family, either extended or foster; they feel their parents take less care of them or even that they have lost their place in the family.

Caregivers have to cope with psychological and behavioural difficulties of the children and teenagers, educational delays for the very deprived one and with special medical treatment. The dimension that all these families (EF and FF) share is the day-to-day organisation required to deal with the infection: a succession of periods of relapse followed by medical emergencies, the necessity to maintain confidentiality of the child's HIV status, the fear of stigmatisation or even rejection of the child, and at the same time, the desire to share the secret with close relatives or friends. The issue of the child's suffering is a difficult one for those who are concerned. In EFs, the heavy constraints of the treatment and medical follow-up is borne solely by the grandmothers and aunts, whereas foster carers have the support of the social team or fostering professionals.

Within EFs, the uncertainty linked to the life expectancy of the sick child and the years remaining to the grandparents is another source of anxiety: *"I hope I'll survive long enough to be able to take care of him..."* More than half the grandparents interviewed had no specialised psychological backup. The presence of a spouse and relatives is not always enough to help them cope with the trial that the future death of the child who represent. Families rarely turn to voluntary associations, as their needs tend to require an immediate response or help with solving a concrete problem arising from the child's illness. FFs, on the other hand, have the advantage of a specialised psycho-educational and therapeutic support system, designed to help them not only cope with the care management of the disease and its impact on the other members of the family, but also with the complicated relationship with sick parents. However, this support system is more or less effective from region to region and depends on whether or not they are working with a simple foster agency or a foster agency with specialised psychological or psychiatric backup.

Conclusion

Kinship and foster care represent the two social responses to the issue of the outcome of children who have lost or risk losing their mother and/or father to AIDS. One is a private response based on family support, where the kinship care of grandchildren, nephews or nieces follows on from the ties of affection and the history of the parental illness. The other is a public sector response, the result of an informed choice made for philanthropic reasons, incorporated into a structured and supportive institutional framework. Once these differences are set aside, the involvement of both parties, as well in educational as emotional terms, is roughly the same, particularly in terms of anxiety about the disease and the future of the child.

One of the pitfalls of the institutional care system is the focusing on the disease by the teams and inexperienced FFs, while ignoring the behavioural and psychological problems of the child or teenager and sometimes their specific backgrounds. For all FFs, in particular the new ones, when the mediator role normally played by the foster agency is insufficient and when the child is seriously ill, the emotional impact is so strong that the entire family cell can be seriously endangered. It may sometimes lead to the failure of the placement. The same risks of

extreme involvement may occurs in EFs, especially with grandparents; however, they will not put an end to their care: *"We have a mission and we will carry it out at any the cost."*

The results of the national survey have shown that there is a low rate of HIV-infected children (2.5‰ in Paris). Because of the new drug-treatments during pregnancies, there are less births of HIV-positive babies. Despite this fact, there are still new children in care: these are older ones and above all they are African, large-sibling children. Permanency planning still represents important coordinated efforts involving healthcare and mental professionals, social workers, foster agencies, legal personals, the biological family and surrogate one, and after the placement, the foster carers. Successful initiatives to identify appropriate families for short-or long-term care should be developed as well as the ongoing training for carers. Psychosocial and financial support must be more adapted to the extended families. Flexibility between social and medical staffs for HIV-infected children in care should be enhanced.

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Table 1 National survey: characteristics of HIV-infected chidren in care
(including those who had left within less than 2 years)

	Total		Geographical origin of the mother		
	n	%	Europe	North Afr. DOM*	Sub-Sah. Africa**
Birth year (n=98)			(n=43)	(n=20)	(n=30)
1978-79	2	2.0	1	-	1
1980-84	12	12.2	2	3	7
1985-89	32	32.7	13	10	9
1990-94	43	43.9	20	6	12
≥ 1995	9	9.2	7	1	1
Age of admission in care (n=95)			(n=46)	(n=19)	(n=29)
< 1	23	24.2	9	9	5
1 – 3	28	29.4	15	4	8
4 – 5	20	21.1	10	4	6
6 – 9	15	15.8	9	2	4
≥ 10	9	9.4	3	-	6
Parental situation (95 M, 92 F)					
unknown or dead mother	38	40.0	14	7	16
unknown or dead father	43	46.7	17	12	14
unknown or dead M and F	21	22.8			
Administrative status (n=98)			(n=45)	(n=20)	(n=30)
temporary care	25	25.5	16	2	7
court orders	53	54.1	25	14	11
Wards	20	20.4	4	4	12
Siblings (n=89)			(n=42)	(n=20)	(n=26)
No	33	37.1	15	6	12
yes *(including those in care)*	56 *(42)*	62.9 *(47.2)*	27 *(21)*	14 *(11)*	14 *(9)*
			(n=48)	(n=20)	(n=30)
Living within (n=101)					
foster families	57	56.4	24	14	18
Institutions	27	26.7	16	3	8
ex-care	17	16.8	8	3	4

*Département d'Outre Mer (French Carribean Islands),
** including a Haitian child
For each variable, the "no" answers were not taken into account. Consequently it explains the differences between samples and the overall total.

Table 2 Characteristics of extended families (EF) and foster families (FF)

Characteristics of the families	Grandparents (n=24)	Uncles, aunts (n=12)	Foster families (n=20)
Age (women)			
<39 years	-	4	2
40-49	2	6	10
50-59	12	1	7
60-69	8	-	1
≥ 70	2	-	-
Parental socio-status			
Farmers	1	-	-
self-employed, shopkeepers	2	-	1
upper management, professional	-	4	5
Middle management	6	1	8
workers, employees	15	7	6
Financial resources*			
< 5 000 FF.	3	1	2
5 000 - 9 999 FF.	10	4	9
10 000 - 14 999 FF.	7	3	2
$\geq 15\ 000$ FF.	4	4	7
Caretakers legal roles	(by family)	(by family)	(by child)
no legal relationship	4	1	-
legal custody	11	6	-
temporary care	-	-	2
Guardianship	5	1	10
kinship care	2	1	-
Adoption	2	3	2
Wards	-	-	10

*For EF: wages, pension, family and social allowances. For FF: all resources except foster carer salary.

Table 3 HIV positive children's characteristics

Characteristics of the children in	Extended families	Foster families
Age		
< 3 years	3	2
3 – 5	12	10
6 – 8	12	6
≥ 9	25	6
Changes in home environment		
2 changes	16	4
3 changes	15	10
4 changes	17	7
≥ 5 home	4	3
Mother's geographic origins		
Europe	14	10
Maghreb	4	2
Caribbean	4	3
Sub-Saharan Africa	4	9
Total	52 *(27 HIV+)*	24 *(all HIV+)*