Meeting health and ethnic needs in placement: Planning for African children affected by HIV

Based on their experience as workers with the London-based Barnardo’s Positive Options Project, Joan Fratter and Benigna Kiwanuka Ndagire discuss practice and policy issues arising from the need to plan for African children whose primary carers are living with HIV. They argue that what they have learned from African parents, carers, young people and children affected by the virus could be applied to families with children from a range of minority ethnic groups who are experiencing similar suffering and uncertainty through HIV or another life-threatening illness. A growing demand for the appropriate recruitment, training and support of permanent and ‘flexible’ foster carers is emphasised, as is the overall importance of ensuring that health factors and ethnicity are fully incorporated into planning to meet the needs of the whole child.

Introduction
This paper explores practice and policy issues in planning placements of children whose primary carers are living with HIV and who may therefore be orphaned before they reach independence. It derives from the experience of workers in Barnardo’s Positive Options Project, which was set up in 1991 to offer a social work service to families with children affected by HIV. Since that time, intensive or long-term work has been undertaken with almost 300 families, mostly in London. The main focus of work has been to enable parents and carers to plan for their children’s future care. About three-quarters of the families with whom the Project has been involved originate from Sub-Saharan Africa.* Most are asylum seekers. In this respect, the work of Positive Options and of other voluntary and statutory HIV agencies in London is different from the experience in other parts of the UK, particularly in Scotland. What we have learned from African parents, carers, young people and children affected by HIV could be applied to families with children from a range of minority ethnic groups who are living under the shadow of HIV or another life-threatening illness. Consideration of health factors and ethnicity is integral to planning to meet the needs of the whole child.

The impact of HIV on children and young people
Most children whose primary carers have a life-threatening medical condition experience loss and change in their life. However, there are likely to be additional issues for children whose primary carers have HIV, particularly those from black and minority ethnic families, including asylum seekers. Children and young people in such families, a minority of whom are themselves HIV+, may experience:

- isolation (because of the stigma and secrecy associated with HIV and lack of extended family available) – ‘I wish my auntie lived here. It’s not as if I can tell any of my friends. I don’t invite them home when Mum is ill. What do I say?’ (Girl aged 12);
- racism (exacerbated by the widespread belief that HIV originated in Africa);
- the effects of having had to leave their country of origin, possibly in traumatic circumstances;
- excessive responsibility as young carers – ‘It’s awkward not being able to explain why I’m late for school when Mum’s not well and I’ve had to take [my younger sisters] to school first, go to the chemist, whatever.’ (Girl aged 13);
- problems in school associated with language difficulties, teacher expectations and/or poor school attendance;

*Sub-Saharan refers to Southern, Central and East Africa.

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• insecurity and separation from family members, including brothers and sisters, as a result of immigration laws – ‘I’m really scared that the Home Office might say my auntie has got to go back to Uganda once her visitor’s visa is up. I don’t know how I’d manage to look after the boys without her.’ (Young woman of 17 who has assumed responsibility as head of the household since her parents’ death);

• the distress of living with primary carers who are chronically ill and of experiencing the death of one or more family members – ‘Sometimes I wish I didn’t know about Mum being HIV. I get really scared if she has flu or something.’ (Girl aged 12 who has vivid memories of her father being ill and of his death);

• stress associated with medication and treatment for children who are HIV+ – ‘He’s always asking why I make him take the medication. He gets angry. He says I don’t like him.’ (Mother of boy aged 7);

• psychological issues for older children and teenagers living with HIV – ‘I wish our mother had told me about her illness and my younger brother’s illness. It would have helped us to grieve.’ (Girl aged 15 whose mother and baby brother had died).

Chinouya-Mudari and O’Brien (1999) highlight the ‘loss of childhood’ experienced by African children affected by HIV in London and their difficulties in expressing their feelings about their experiences:

Notwithstanding the cultural diversity between and within African children, the need to communicate stress associated with caring roles may be compounded by the fact that, culturally, the disclosure of family circumstances to ‘strangers’ may be inappropriate. (p 28)

Changes in placement needs for African children affected by HIV since 1997

With the improvement in the medical treatment of HIV-related illnesses and the development of combination therapies in recent years, a substantial proportion of the parents with whom we work at Positive Options are living longer with the virus and are in better health. Currently the most evident placement needs for children living in families affected by HIV are for flexible short breaks, for long-term care or for linking with a short-breaks carer who could also provide permanent care in the future if necessary.

Flexible foster care

Flexible (short breaks) foster care, either in the carer’s or the child’s home, may be required when the prospective guardian or long-term carer does not live locally and:

• a parent (or primary carer if the parent has already died) is embarking on new treatments and temporarily experiencing debilitating side effects;

• a child is HIV+ and her or his parents need support to cope with the demands of the child’s treatment regime;

• an unwell parent is caring for an HIV+ child who is reacting with challenging behaviour to the treatment regime and/or to having learned about the HIV diagnosis;

• a parent’s treatment is unsuccessful.

As well as meeting a child’s health and ethnic needs, flexible care needs to be available in an emergency, to be locally based and to accommodate brothers and sisters together. Continuity is especially important for children who have already experienced loss and change. The effects of frequent periods of separation from the primary carer can be reduced if the same carer can accommodate or stay with the children on each occasion. It has in some instances proved difficult for hard-pressed fostering teams to provide this continuity: one parent was told that her daughter would be looked after by whoever of four potential foster carers ‘had a vacancy’ when the need arose.

Permanent foster care

Despite the fact that the new HIV anti-retroviral triple therapies have led to a considerable improvement in the general health of people living with HIV, there are
individuals who have not benefited from these medical advances. We are still working with parents who are very ill and dying and whose children are not yet independent. Permanent foster care placements are needed when there are no relatives or community members available. Adoption has rarely been considered for Sub-Saharan African children in need of a permanent placement. Severing a child legally from the clan would be regarded as depriving a child of her or his birthright (African Issues Group, 1995; Matovu et al., 1998; Coram Family, 1999). In families in which surviving children are in their teens, it has occasionally been possible to recruit a non-related carer to live with the children in their own home until they are independent (Fratter, 1993).

**Short breaks leading to permanent care**

Short breaks leading to permanent care have been an effective way of providing continuity for a minority of children who have no relatives able to provide care in the short or the longer term. A foster carer not previously known to the family looks after the children for short periods (in the family or the carer’s home) when a parent is unwell or needs a break. This should ensure that when the children need care on a long-term basis, they have already developed a relationship with a carer whom the parent has been able to get to know. As well as providing continuity for the children, this gives reassurance to a parent whose health is uncertain:

_Social services haven’t sorted out anything, even now. If anything happens to me, I don’t know what would happen to the children… no one can tell with the virus – people are still dying and leaving the children without knowing who’s going to look after them… if you had a foster mother, you know you’re fighting the virus together. She’s coming to the hospital to see you; she’s seeing you in your own house; she’s seeing how things are going with the children so that she can help them in the future. It would be nice to work together with the foster mother and the child as well._

**Planning**

Planning is undertaken within the framework of the Children Act 1989 (England and Wales). However, there may be some particular challenges in fulfilling legislative requirements while respecting African child-rearing practices and the concerns about confidentiality expressed by many parents living with HIV:

- Efforts must be made to maintain the child within the immediate or extended family, but a parent may initially be reluctant to disclose information about kin living in the UK because of fears about her or his HIV status becoming known within the community.

- Account should be taken of a child’s race, language, religion and culture, but this may be particularly complex because of the diversity of the background and heritage of the children, particularly those whose parents are from different African countries or different ethnic groups in the same country.

- A child’s or young person’s wishes and feelings must be ascertained in relation to important decisions (Orr, 1995). However, children in African communities are traditionally protected from involvement in decisions which are seen as the responsibility of adults in the clan (Namusisi, 1995) and parents may not welcome the direct involvement of a professional with their children.

- Working in partnership with parents and family members may be hampered by a reluctance to engage in discussions with a stranger, particularly from a different racial and cultural background.

In all cases, planning for their child’s future care is likely to be a painful and lengthy process for parents. They will need to have developed a relationship of trust with a worker and be ready to acknowledge the possibility of the loss, through premature death, of their future with their children.

**Exploring and supporting placement options within the extended family**

The options which can potentially be considered for a child’s future care within
the extended family or community include living with relatives or friends through informal agreement or through more formal arrangements – guardianship, foster care, residence order or (exceptionally) adoption. It is important that parents and prospective carers are given clear information, verbally and in writing if they wish, about the different legal and financial status associated with each of these arrangements. The concept of adoption, for example, is understood differently by many individuals from Sub-Saharan African communities compared with a formalised UK model. Lack of suitable accommodation to foster may be a particular obstacle for individuals who are members of newly arrived African communities, particularly those whose asylum status is still to be determined. In addition, they may be awaiting, five or more years after their asylum application, a Home Office decision as to whether they and their children will be allowed to remain in the UK.

However, extended family may be able to offer support, in the short or long term, by providing care on a flexible basis, in the children’s own home. In working with African families and other families from minority ethnic groups, there is a need for:

- culturally sensitive assessments – ‘Many of the questions asked are viewed by most African applicants as offensive and intrusive.’ (Feldman and Ndofor-Tah, 1997, p 20);
- consideration of how uncertain immigration status will affect the children for whom they care – it is hard for carers to provide a secure environment when their own future is uncertain;
- support on childcare issues, including developing an understanding of the differences between child rearing in an African culture and a Western culture;
- ensuring the collective family blessing for a child’s placement rather than pursuing an individualistic approach.

Traditionally, in a patrilineal culture, the father’s relatives would be very much involved in determining a child’s future care arrangements, even if he has not been in contact with his child or has already died. To overlook this could result later in conflict and be unsettling to the child and undermining of the carer. These aspects of planning were explored in detail from an African perspective by Matovu et al (1998).

**Placement with non-related carers**

A few African parents have initially requested placement with a white family, influenced not just by fears of a breach of confidentiality among community members but also by concerns that an identified carer from the community may also prove to be HIV+ (and indeed it has been known for a few children to have had a succession of placements after the death of a parent as subsequent carers have also died). Some African parents’ expressed preference for a white foster or adoptive family derives from their perception that their child would thereby have a more secure future (educationally and financially) or from ‘colonial’ notions of white superiority. Such requests need to be discussed sensitively with parents. In our experience, parents have welcomed information and the opportunity to explore the reasons underlying the Children Act provisions about the placement of black children and children from minority ethnic groups with carers of similar ethnicity. A parent who had initially considered nominating a white member of her church as sole guardian of her son eventually appointed the church member as joint guardian with a male relative living in the North of England. The parent’s decision was influenced by her son’s wishes, by having the opportunity to consider his needs holistically, by the views of her family ‘back home’ and by the prospective white guardian’s own preference for a joint appointment.

In a few instances, it has been necessary for a parent to give weighting to different needs; for example, whether or not a carer is available who fully reflects the child’s heritage, religion, race or culture may be seen by a parent as more important for a particular child.
Some African parents affected by HIV have found their child linked to a ‘black’ family, irrespective of issues of language, ethnicity and culture, and have been told that such a placement is regarded as ‘culturally appropriate’.

A parent working with Positive Options asked the care manager to recognise that culturally Africans are not a homogeneous group, even though there are similarities between some ethnic and national communities. In discussion of models of care, Kaniuk and Lindsay Smith (1999) point out that it is crucial ‘to ask parents which factors – such as cultural background, religion, political affiliation, language, tribe and clan – they consider most important to match in the carer’ (p 24).

Progress

There has been some progress in London in recent years in recruiting African carers for both affected children and children who are themselves HIV+. Currently, some successful initiatives have been developed to identify appropriate families, through outreach to members of Sub-Saharan African communities (Feldman and Ndofor-Tah, 1997; NFCA, 1997; Coram Family, 1999). Most boroughs with significant numbers of African families affected by HIV have appointed African workers to their Family Placement Teams, some having a brief to develop a flexible short-breaks service. African community-based organisations from several Sub-Saharan African countries have been particularly proactive in alerting communities to the needs of orphaned children and of children living in families affected by HIV.

However, the response of agencies – their approach to preparation and assessment – has to take account of the special circumstances of asylum seekers from Sub-Saharan Africa (Terrence Higgins Trust, 1999). Harber’s account of recruiting carers for orphaned children in South Africa (1999) demonstrates how a Eurocentric model of assessment can be adapted so as to build on the strengths of African families. Kaniuk and Lindsay Smith, describing the experiences of the Coram HIV Project (1999), point out that ‘effective working will depend on adapting – but not diminishing – the good practice of established homefinding agencies’ (p 31). They highlight the need to:

. . . re-educate panel members and medical and legal advisers so that they will not automatically rule out applications from prospective carers whose history and present circumstances are a catalogue of losses and adversity.

Policy and practice implications

Recruitment, training and support of foster carers to care for HIV-affected children need to be undertaken within a clear agency policy and procedural framework of awareness of ethnic needs. It is important to ensure that HIV awareness is on the agenda whenever foster carers are undertaking preparation and training.

Agencies can promote good practice in placements for children affected by HIV by developing guidelines regarding:

- the importance of meeting a child’s ethnic and cultural needs;
- confidentiality (HIV status of a child or parent should only be disclosed with parental agreement and if to do so would promote the child’s welfare);
- the testing of a child for HIV – if the parent of a looked after child is unwilling or not available to give agreement to a child’s being tested, legal advice should be sought;
- the need to access the knowledge and skills of professionals and community members who reflect the diverse ethnic and cultural backgrounds of affected families;
- the training of panel members who may be unfamiliar with issues affecting asylum seekers and the impact of HIV on Sub-Saharan African communities;
- ongoing training for carers to take account of developing knowledge and to include emotional as well as practical and medical aspects of HIV, preparation for
working with children facing bereavement and understanding of the stigma, discrimination and prejudice which HIV attracts;

- the availability of a support group for carers and of access to someone with specialist knowledge;

- adequate support (practical, financial and emotional) for relatives (Regulation 11 carers), who often receive limited or no support, even when they are caring for two or more orphaned children;

- respecting the emotional and psychological needs of a child who is HIV+, as well as meeting her or his health needs.

Carers of HIV-affected children, as for other children in need (Barn, 1999), must be recruited from a wide range of cultural and ethnic backgrounds. However, in a context in which HIV-affected families may have originated from one of ten African countries, in some of which several languages are spoken, placing in a way which meets the needs of the whole child may be particularly complex. Workers need to consult widely with the child’s parents, with the family network and with community members in order to develop a strategy which best meets each child’s needs.

Note
BAAF has recently published Practice Note 39, *Hepatitis and HIV: Issues related to substitute care, foster, residential care and adoption*, available from BAAF Publications. Price £1.00 (plus 30 pence p & p).

References


