



# Positively Caring

Ensuring that positive choices can be made about  
the care of children affected by HIV

**EveryChild.**

## Acknowledgements

This report was written for EveryChild by a consultant, Siân Long, with inputs from Emily Delap, EveryChild's Global Policy Advisor, who also managed the research process. The report is based on a literature review carried out by Siân Long, and findings from research in India, Malawi and Ukraine. The research in India was managed by Payal Saksena, and data collection was carried out by partner NGO, Arogya Agam. The research in Malawi was managed by Brussels Mughogho, Keston Ndhlovu and Nicodemeous Mphande. The research in Ukraine was managed by Oksana Shved and Yulia Galustyan. In both Malawi and Ukraine, national networks of people living with HIV and AIDS made valuable contributions to research design and providing access to research participants. Thanks go to the All-Ukrainian Network of People Living with HIV/AIDS and the National Association of People Living with HIV and AIDS Malawi. Anna Wansbrough-Jones from EveryChild head office assisted with data analysis, country-level report writing and editing of this report, and Marianne Sladowsky made valuable contributions to the policy recommendations.

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**The names of the children in this publication have been changed in order to protect their identities. Fully informed consent has been obtained to use the stories and images featured in this publication. The images of children used in this publication do not indicate a positive HIV status unless explicitly stated in the photo caption.**

### Front cover image

Agnes is a single mother living with HIV. She looks after her two sons and her sister's three children. Looking after five children on her own, along with the added financial burden of living with HIV, has left the family very poor. A year ago, her 10-year-old son Mtenje (*pictured on the front cover*) dropped out of school to earn money herding cattle to support the family. EveryChild intervened and he is now back at school. Agnes was also encouraged by EveryChild to form a local network of people affected by HIV and she has become a passionate campaigner about HIV issues in her local community.

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# Summary

This report examines the impacts of HIV on the care choices of children, exploring how HIV affects whether or not children can remain within parental care, and on the alternative care options open to them. It is based on qualitative research in Malawi, India and Ukraine, and on a global literature review. It is in response to alarming global evidence on the rising numbers of children outside of parental care, and growing global recognition that responses to HIV should centre on increased support to families as the best means of providing care and protection for children (EveryChild 2009b; JLICA 2009).

The research findings point towards four key conclusions:

## **The care choices of children affected by HIV are constrained**

Children affected by HIV do not currently have the same care choices as other children. They are more vulnerable to losing their parents at an early age, often due to inadequate access to Anti-Retroviral Therapy (ART). HIV-related ill-health, discrimination, poverty and stress can also have indirect impacts on the numbers of children outside of parental care, contributing to the complex range of risk factors which push children away from families. Children affected by HIV may be denied extended family care, access to some residential care facilities, foster care and adoption because of discrimination, or misguided worries about HIV-positive children infecting other children or requiring specialist medical care. In Sub-Saharan Africa in particular, HIV is in part responsible for a changing care landscape, as the growing number of children orphaned by HIV related illness is being used as a rationale for the unchecked expansion of many different forms of residential care.

## **Children affected by HIV should have the same care choices open to them as other children**

Children affected by HIV, like all children, should be able to stay with parents unless it is in their best interest to be separated. Where this is not possible, it should be recognised that extended families currently care for the vast majority of children outside of parental care in many settings, and offer a positive choice for many children. HIV-affected children outside of family care should be offered the same range of care options as other children. Residential care, particularly large-scale, dormitory-style care, should be used with extreme caution, and decisions about which residential care facilities are used should be based on considerations of a range of children's needs and not just their HIV status. Foster care can offer a positive short-term family-based care option for children, and adoption can be used as a permanent solution for children who are without parental care. Where foster care and adoption are used, efforts should be made to ensure that HIV-affected children are able to access these forms of care in the same way as other children.

## **Families affected by HIV need more support to care for children**

Families affected by HIV need to be offered more support to care for children, and whilst many of these support needs are similar to the support needs for other vulnerable families, HIV-affected families do face some particular challenges. For example, bouts of ill-health combined with poor access to health care make it particularly hard for HIV-positive carers to earn a regular income. Discrimination against HIV-positive adults prevents access to work or basic services. Discrimination and health worries places an enormous psychological burden on

carers and children alike, leading to stress, and in some cases, conflict in the home. Caring for an HIV-positive child can cause particular anxiety, and increase the need to access health care services and provide nutritious food for the family. Child care responsibilities make it especially hard to travel long distances to get necessary medical treatment.

**In providing support to families, it is essential to recognise differences between family types**

In supporting HIV-affected, and indeed any vulnerable family, it is essential to recognise differences between family types. For example, grandparent carers often offer enormous love and emotional support to children, but may struggle with poverty. Children in aunt or uncle care or living with older married siblings may be more likely to suffer from abuse and discrimination than those in grandparent care. Children in step-families are particularly vulnerable to family separation. Women in all kinds of families take on the bulk of responsibility for children's care, and in many instances bring up their own children, and their grandchildren, nieces, nephews or siblings with minimal male support. Some men do struggle against social norms and bring up children alone. In all cases, single-parent/ single-carer households have particular support needs.

These conclusions point towards five key policy recommendations for governments, donors, UN agencies and non-governmental organisations:

1. Children affected by HIV must have the same positive care choices as other children through enabling families to provide care for children affected by HIV, reducing the reliance on harmful forms of residential care, and ensuring that alternative family-based care<sup>1</sup> options are not closed to children affected by HIV.
2. Families affected by HIV must be given more support to care for children through greater social protection, increased access to services, and other support tailored to the particular needs of different types of families.
3. There must be greater investment in inclusive child protection and alternative care, and such service providers must recognise the particular needs of children and families affected by HIV.
4. Discrimination on the grounds of gender or HIV status in communities and families must be challenged.
5. The impacts of discrimination on the grounds of HIV, and indeed due to other factors, such as gender and disability, on children's care choices must be systematically monitored to assess progress in enabling all children to have positive care choices.

<sup>1</sup> These options include guardianship, extended family care, foster care (in the short-term) and adoption.

# 1 Introduction

A loss of parental care and being affected by HIV are both devastating situations for children and both are well documented. Less known are the links between these two issues, and what effect HIV has on children's care choices. This is the focus of this report.

The HIV pandemic has had a enormous impact on the lives of children and adults around the world, with millions of boys and girls left without one or both of their parents as a result of the disease. The impact of HIV has been most felt in Sub-Saharan Africa, home to over three-quarters of children who have lost one or both parents to HIV related illness (more than 14 million children) and 91% of all new paediatric infections (Foster, Laugharn & Wilkinson-Maposa, 2010). Although overall HIV prevalence is lower in other areas, it remains a significant problem, especially in countries that have high prevalence amongst 'Most at Risk Populations', often excluded or marginalised communities such as injecting drug users, sex workers or mobile populations.

There is a growing recognition that responses to HIV should not just focus on individual children and adults, but must instead seek to support families who take on most of the responsibility of caring for those affected by the disease (JLICA 2009). Despite the recognised impact of HIV on households already under stress from poverty and food insecurity, it primarily remains families and communities that care for vulnerable children. Families and communities, particularly in worse affected regions, take on most of the care, support and protection of children affected by HIV, and bear around 90% of the

financial costs, often receiving no or limited assistance from the state or other agencies (UNAIDS, 2008; JLICA 2009). International and national policies are starting to include a greater focus on integrated family-based care that addresses the health, income and welfare needs of HIV-affected households.

The recognition of the central role played by families in caring for children affected by HIV coincides with global evidence showing that the number of children without parental care<sup>2</sup> is growing rapidly and that families need more support than ever to stay together. The rising use of residential care, and the lack of family and community based alternatives in many countries also suggests that many children outside of parental care have extremely limited care options (EveryChild 2009a/b).

This report explores the impacts of HIV on children's care choices, and the support needed to enable the often preferred choice of family-based care. It is based on a global literature review and three pieces of research conducted by EveryChild and its partners in India, Malawi and Ukraine. Following a description of the research methods, the report presents the research findings in two sections. Firstly, it contrasts preferred care choices for children affected by HIV with actual options open to these girls and boys. Secondly, it explores the support needs required to enable children to remain in family-based care. The report ends with a conclusion summarising research findings and providing detailed policy recommendations.

2 Children without parental care are defined as *all children not in the overnight care of at least one of their parents*. They include children living in residential care, with extended or foster families, in child-only households, in juvenile detention, on the streets without their parents or living with their employers/exploiters and without their parents (EveryChild (2009a)).

# 2 Methodology

## Methods

This report is based on information gathered through field work that was undertaken in Malawi, Ukraine and India and a literature review.<sup>3</sup> Further information on context in these three countries is provided in the box below. The three research initiatives took place in EveryChild or partner agency project sites – rural Bulala area in Mzimba district in Northern Malawi; rural and urban areas of Theni District, Tamil Nadu in India; and Kyiv city, Bila Tserkva city and Poltava city in Ukraine. In India, the research partner was Arogya Agam, a non-governmental organisation (NGO) that began supporting people affected by HIV in the early 1990s. Arogya Agam was responsible for data collection, which was supervised by EveryChild staff. In Malawi, EveryChild conducted the research with assistance from the National Association of People Living with HIV and AIDS Malawi (NAPHAM), Bulala branch. In Ukraine, the All-Ukrainian Network of People Living with

HIV or AIDS (AUN-PLWHA) commented on terms of reference, and helped EveryChild to identify and meet with families affected by HIV.

Each country used a similar methodology. Focus group discussions (FGDs) and/ or in-depth interviews were held with a total of 158 boys and girls living with or affected by HIV and 235 HIV-positive parents and other family caregivers. In India and Malawi, 41 children living in residential care were also included in the research. In addition, a total of 45 policy-makers, local leaders and other stakeholders were interviewed. Annex 1 provides a breakdown on the numbers and types of participants in each country.

The focus group and in-depth interviews were guided by a common checklist of questions and facilitated by a trained research team, comprising of EveryChild staff, graduates recruited especially for this project and/ or research consultants. Efforts were made to speak to an equal number of male and female

## Research context

Malawi's national HIV prevalence is 12% of whom about 10% are children under 15 years. 12% of all Malawian children have lost one or both parents, and around 20% of children are without parental care (NAC 2009; Parry-Williams 2007). Ukraine and India have a lower HIV prevalence, with the epidemic largely focused on 'Most At Risk Populations' (MARPs), notably intravenous drug users, sex workers and, in India, mobile populations. In Malawi, whilst HIV may not be referred to directly and whilst testing levels are relatively low, there seems to be more general acceptance of children who have lost parents. In both India and Ukraine, stigma was a significant barrier to accessing entitlements. The stigma in Ukraine is extreme and was a factor in the research design, with few people being willing to disclose their HIV status even in relatively confidential settings.

<sup>3</sup> The country reports are available from Emily Delap [Emily.Delap@everychild.org.uk](mailto:Emily.Delap@everychild.org.uk)

participants and to gain the views of males and females separately. Participants were selected through those who were already involved with the research organisations.<sup>4</sup> All children who participated were aware of their status if they were HIV-positive and were aware of their parent's HIV-positive status where they had HIV-positive parents.

In all three countries, interviews were also held with local stakeholders. Children already living in residential care and/ or residential care workers, from the project site were interviewed in Ukraine and India. There were no residential institutions in the research site in Malawi but in-depth interviews and focus groups from four randomly selected residential care homes for children in Lilongwe and Blantyre were also held. In all three countries, national level policy-makers and practitioners were also included in the research.

The focus groups used drama and ranking exercises to stimulate discussion. Preliminary analysis of the initial data was summarised to gain feedback from research participants and follow up on some key issues raised.

In addition to the primary research, a rapid desk review of current global literature was also undertaken. Information was sought from the internet using search words such as 'HIV' + 'child\*' + 'alternative care / institutional care / orphanage / parental care'; 'HIV-positive children' + family care'. Literature reviews were also carried out at the national level in Malawi, India and Ukraine.

## Ethical issues

A number of steps were taken to ensure that the research took place in an ethical manner and did not harm participants. The research team received full training on research ethics and child protection issues. Discussions were also held with members of local participating networks of people living with HIV with experience of working on HIV issues. This led to agreed ethical protocols which included:

- a decision to only speak to those already open about their HIV status. In Malawi and Ukraine only those already attending NAPHAM/AUN-PLWHA meetings took part, and India only those already receiving support from the partner NGO were engaged. This ensured that participation in the research itself did not lead to unintended revelations about status. For all three countries, FGDs with adults and children living with HIV were held in places familiar to them, with efforts made to ensure people were present who they were already familiar with and trusted;
- assurances of anonymity, including a commitment not to reveal HIV status and changing identifying details in case studies presented;
- developing a script for explaining the purpose and use of the research, and providing each participant with repeated opportunities to decide whether or not to take part. Parents/ carers were also asked for their consent before children took part in the research;
- adhering to EveryChild's child protection policy to ensure that any child protection breaches could be reported and dealt with;
- having referral procedures to ensure that help could be offered when participants revealed extreme problems or rights violations;
- providing refreshments and carrying out the research at times that suited participants;
- conducting the research in a community where EveryChild or partners already have programmes to ensure that findings are not wasted and can be used to improve interventions;
- In Ukraine, questionnaires and guides for interviews and focus groups were developed in line with 'Ethical Concerns of Conducting Sociology Research among Children in Ukraine' (Association of Sociologists Ukraine 2008).

4 Due to challenges in identifying and gaining access to HIV-affected individuals owing to high levels of stigma and discrimination.



## Constraints

A challenge faced in both the three field studies and the global literature review is that there is 'limited to no systematic, central data collection or collation on children living in informal or formal alternative care situations' (UNICEF 2008b).<sup>5</sup> Information on direct links between HIV status of family members and a child's care situation is even harder to know. For example, in care proceedings, it is not always feasible, and rarely appropriate, to collect information about HIV status of child or caregiver, even where this information is known, which is often not the case.

In all three countries the research sample is small in size – 158 children and 177 caregivers in total. In Ukraine the numbers were particularly small, in part because of the extreme levels of discrimination against HIV-positive people and, in part, due to the lower prevalence rates and low numbers of HIV-positive adults who do know their status. Attempts were made to recruit a larger number of individuals to take part in the research, and although resources were available to do this, it was not possible to find any more willing participants in the three Ukrainian research sites.

Both Ukraine and Malawi found few HIV-positive fathers or male extended family members

involved in the care of children affected by HIV. The possible reasons for this and the implications for child care are discussed below and form part of the recommendations.

The research was not able to include many children living in residential care. In Ukraine, where residential care is widely used, this was in part due to the majority of HIV-affected children in the research site being under five years old, and therefore too young to participate in the focus groups designed for this research. Even where this research happened, it is not possible to draw strong conclusions. Although attempts were made to enable children to talk freely, there were limited opportunities for rapport building and having to conduct interviews and discussions within the residential home is likely to have inhibited responses from children, in particular about any negative views they have about the facility.

Given some of the challenges associated with speaking to substantial numbers of individuals in some of the categories of research participants, the research cannot be seen as a representative sample of the views of families and children affected by HIV. The research draws some key policy conclusions where consistent evidence emerged from the primary research and literature review, and suggests other areas for further, more in-depth research.

<sup>5</sup> The UNICEF report refers to East and Southern Africa but the quote is relevant globally.

# 3 Research findings

## 3.1 Making care choices

In this section of the report, the impact of HIV on choices about children's care is examined. It is argued that although families affected by HIV would prefer to stay together, HIV can make children more vulnerable to a loss of parental care, though the relationship between HIV and a loss of parental care is complex. HIV can also restrict the alternative care choices for children who cannot live with their parents.

### Preferred care choices

#### Parental care as a preferred option

In all three countries most children included in the research indicated that they would prefer to stay with their parents, especially mothers where alive, due to the love, care, affection and support that parents can provide. Many of the children confirmed that they are happiest when they are with their parents:

“I feel happy when I am with my mum, nobody will look after me like my mother.”  
(Boy living with HIV-positive parent, India)

“My mother is always cheerful and open with me. For example, she told me she is HIV-positive and if I wanted to lead a good life, I shouldn't follow peer pressure. I know she loves me and I love her and that's why I want to stay close to her.”  
(17-year-old son of an HIV-positive woman, Malawi)

The children of HIV-positive parents are also clear, and proud, of their central roles as carers and providers. For example, in one focus group in Malawi, teenage boys spoke of a shift in relationships stating that they now support their parents rather than the other way round.

The research clearly demonstrates that parents living with HIV wish to keep their children with them. Whilst this may appear an obvious statement, it is significant given the pressures and expectations from others about how hard it is to care for children whilst living with HIV. Parents in all three countries described how they want their children to stay with them and to grow up in their care with the love and affection they need. In addition to love and care, these parents indicated strong appreciation of their duty as parents. As a result of this, they described how they struggled to keep their children with them despite challenges.

“They are my children. They are my blood. They are god's gift to me. I want to keep them safe. I love them. My disease should not separate me from the people I love the most.”

(HIV-positive father, Malawi)



Margaret (far left) is a widow living with HIV and is bringing up four children on her own.

Parents were clear about their rights and desire to provide care and support and, more so in the case of fathers, to guide and discipline children. Parents also expressed concerns about the treatment of their children in other forms of care:

▲▲ **Let me die because of HIV, not because of worries because my children are being ill-treated elsewhere.** ▲▲

(HIV-positive mother, Malawi)

Although the primary reason for keeping a family together was love, care and parental responsibility, parents and caregivers recognised the help and support that children can provide and the role that children can play by providing care for their sick parents and / or bringing in an income:

▲▲ **This child is now my hand. Without her, how will I survive?** ▲▲

(HIV-positive mother, Malawi)

▲▲ **I am lacking real manpower at my house because of their absence.** ▲▲

(HIV-positive father, Malawi, whose children are currently in extended family care)

The importance of keeping children in parental care is also recognised in the global literature and acknowledged in the UN Convention on the Rights of the Child (UNCRC), which states that children should not be separated from parents against their will unless it is their best interest to be so. Evidence clearly shows that a loss of parental care can have major consequences for children's survival, education and development, and health (see EveryChild et al 2010). Of particular relevance to this report is evidence that being apart from parents can expose children to drug use, early sexual activity and sexual abuse, increasing vulnerability to HIV infection (Cluver & Operario, 2008; EveryChild 2010).<sup>6</sup> Although many publications in the global literature focus on the challenges of children living in poverty with HIV-positive carers, there is growing evidence from children themselves of positive experiences living in HIV-affected families (see Clacherty 2008, Skovdal 2010 and Save the Children 2010).

Children often express a strong desire to stay with a parent or grandparent, even when things are very tough, a factor that is often underestimated by community members (see for example, Mann 2004).

### **Extended family care as a second choice, especially with grandparents**

In all three countries the first choice of primary caregiver when children cannot be with a parent is the grandmother. This confirms global findings that show that children will usually choose to live with a grandmother 'because she gives me love' (Mann, 2004; HelpAge International 2008; Clacherty, 2008; Loewenson et al, 2008). Both children themselves and caregivers feel that grandparents provide the strongest care and support. For HIV-affected children the research suggests that the care and affection for grandchildren often overrides financial concerns or worries around AIDS. In India, both boys and girls spoke of the strong relationships they have with their grandparents:

▲▲ **I like to be with my grandmother. When I am with my mother I used to cry that my grandmother was not with me.** ▲▲

(Girl affected by HIV, India)

In Malawi, both adult and child participants spoke of grandmothers being especially loving and caring, and often more indulgent than the children's own parents would be. Grandparents were also described as passing on skills, and providing children with good moral guidance. This love and affection was often reciprocated by children, with carers talking of the joys of bringing up these girls and boys, and of them being 'like their own children.' Many boys and girls acknowledge and value the help they have received and showed a debt of gratitude towards those that had cared for them well:

▲▲ **I want to buy them a car one day and build them a nice house, but only if I get a good education. That is my wish.** ▲▲

(17-year-old boy describing what he would like to do for his grandparents who have cared for him from an early age, Malawi)

<sup>6</sup> For example, a recent study of 15 to 19-year-old street children in St Petersburg found that almost 40 per cent of them were HIV-positive. Injecting drug use was found to be the strongest risk factor, with a greater than twentyfold increased risk of HIV (UNICEF, 2010).

In all three countries, the research suggests that living with aunts and uncles or siblings is a less common and less preferred option to grandparent care. As shown below, both children and adults reported greater levels of discrimination against HIV-affected children in aunt and uncle care compared with grandparent care, with some children being denied care altogether by aunts and uncles. There is also some evidence to suggest that abuse and exploitation may be more common in aunt, uncle and sibling care than in grandparent care.

“**They (grandparents) are able to welcome them (HIV-affected children). They are worried about the child’s care and love. Others do not care. They only worry about the disease.**” (NGO Programme Manager, India)

There is much recognition of the value of extended family care in global guidance on the care of children without parental care, with an acknowledgement that for many children this offers the best alternative when parental care is not available or suitable (UN 2009; Save the Children 2007). Extended family care can offer children love, affection, stability and continued links to communities, all of which are important for healthy upbringings (EveryChild 2009a).

### **Views on residential care and other forms of alternative care**

Several of the research participants expressed positive views about residential care. In India, residential care for children was a preferred second choice after grandmothers and before living with an aunt or uncle. This feedback was expressed not just by adults but by children also, and around half of the participating children affected by HIV currently in family care in the Indian research said that if they cannot live with their parents they would prefer to live in residential care.<sup>7</sup> The main reasons given were that education is provided within residential care, and that placing children in residential care can relieve the burden on the family in terms of providing food and shelter. The research

suggests that perhaps it can be said in certain cases children and adults see residential care as a better and safer option than living with other family members, such as uncles and aunts.

“**(Short term residential care) is best because we can get all our basic needs.**” (Boy living with HIV-positive parent, India)

“**We can get all the happiness (from the residential care).**” (Girl living with HIV-positive parent, India)

In Malawi, the community where the bulk of the research took place did not have residential care facilities, and participants had insufficient knowledge to express views about the use of this form of care. However, children in residential care in Lilongwe and Blantyre, some policy-makers, and residential care staff, commonly reported many benefits to residential care, particularly in relation to meeting basic needs, health and education.

In Ukraine, experts interviewed for this report argue that the majority of parents and many child care professionals have very negative views about residential care for all children, including those affected by HIV. However, some staff working in residential care expressed concerns about HIV-positive children’s health care being met outside of residential care and suggested that children would be better off in residential care.

“**We have enough meat and milk products, everything is fresh, we have fruit, juices and child nutrition, 24-hour medical services, screening by professionals twice a year, we consult, we examine them, we take them to Kyiv ... clinics and institutes – for us all doors are opened. Everybody treats us very kindly and helps a lot, provide recommendations etc. When a child is returned to a family or placed in family-typed care – it’s over. We know about child health problems, we know that we have to take him or her to Kyiv to the cardiology centre for instance, we know for sure that mothers won’t do that.**” (Medical worker from a baby home, Ukraine).

<sup>7</sup> It should be noted that it was mostly children in family-based care who expressed these views, and had larger numbers of children currently in residential care been included in the research, outcomes may have been different.





Children living in residential care in Ukraine.

A review of the literature suggests that these positive perceptions of residential care are not just restricted to HIV-affected children and communities, and are also common in other countries. Residential care is often seen to offer a better care option than parental care, by both communities and some child care professionals (see Bilson and Cox 2007; FHI 2010; Evans 2009).

Despite some positive perceptions about residential care, the research raised numerous reasons to question whether this form of care should be viewed as a preferred option.

First, as noted above, families affected by HIV do want to stay together, and as noted below, are generally more than capable of caring for children, including HIV-positive children, if given the right support. Thus, it may well be the case that if issues of poverty, discrimination and access to services were addressed through provision in the community, positive perceptions of residential care would change. This argument is further supported by the views of children in residential care who spoke of missing their parents and other family members, particularly

when visits to the home were rare, as was the case in India in particular. Parents also spoke of missing their children, and some staff argued that many children would prefer to be in their own homes:

“Given the choice probably the child would like to go back to their natural roots... only one child from here did not want to go back because of her father.”

(Staff at NGO residential care centre, India)

Second, some NGO staff spoken to in India noted that the existence of a highly regarded residential care facility in Theni acts as a magnet, encouraging parents and carers to place children in residential care, even when family-based care could offer a better option. Staff from partner NGO, Arogya Agam, have noted that once community-based family support programmes were put into place, the number of children referred to this particular facility fell.

Third, some parents in India spoke of the high level of punishment that children face in some residential care facilities and the

risks of exploitation. Echoing this, two of the participating boys who are in residential care spoke of being beaten if they do not study.

Fourth, it was noted that proper procedures for managing children's entry into and exit from residential care were not always followed. This suggests that decisions about entry into residential care, and in particular about the possibility of supporting children in families and communities, may not have been properly thought through. For example, in Malawi children were actively recruited into one home, suggesting that the home may be causing rather than responding to a lack of family-based care. Children were expelled from homes if they misbehaved and, in some cases, follow-up support was not provided. In several of the homes visited, children were encouraged to stay for as long as they needed to complete their schooling, and regular reviews of their care needs and opportunities to return to supported family-based care were not provided. Similarly, in India, entry into residential care was often based on the need to provide children with schooling, rather than because of the lack of appropriate family-based care.

Finally, the literature review in Ukraine challenges the idea that HIV-positive children will be better cared for in residential care. Researchers from Leiden University found that family care, even of compromised quality, was more favourable for children's physical and cognitive development than institutional care. HIV-infected children brought up in disadvantaged families showed better physical and cognitive development not only in comparison to HIV-infected children in residential care, but also compared to non-infected relatively healthy children reared in institutions providing good quality physical environments (Dobrova-Krol et al 2010).

These questions about the use of residential care are confirmed by much of the global evidence base, which provides extensive evidence on the harm caused by residential care, particularly long-term care in large, dormitory-style institutions. Such residential care can leave children vulnerable to abuse and exploitation, and can also cause developmental delays if children are unable to form a loving bond with

a particular carer. This care is also expensive, much more so than supported family-based care in the community (Browne 2009; Johnson et al 2006; Bilson 2009). As indicated by the research, the growth and use of residential care in many parts of the world is unregulated, with limited attention paid to ensuring that children are only placed in residential care when efforts to support and assist families have been exhausted (BCN et al a/b; UNICEF 2008a/b; Evans 2009). Suggestions that the use of residential care should be limited are also supported by the UN Guidelines on Alternative Care (2009).

Arguments about the harm caused by residential care do not mean that it should never be considered as an option for children affected by HIV. As shown below, in a minority of cases, children in both extended family and parental care suffer from abuse, neglect and discrimination. If alternative family-based care cannot be found for such children, residential care may offer the best opportunity to ensure that they are cared for and protected, particularly in settings where foster care or adoption services are poorly developed. Where possible, such care should always be provided in small group facilities, embedded in communities, as such homes appear to offer the best opportunities for children to form bonds with carers and links to communities (see World Vision 2009).

Participants did not express views about other forms of alternative care during the research, partially because in Malawi and India in particular, options such as formal foster care or adoption are rarely used. Research, and the experiences of EveryChild programmes around the world, suggests that foster care can provide a family-based alternative to residential care for the short-term care of children who are without parental care, particularly in settings or situations where extended family care is not an option. Adoption is used to provide children who are without parental care with a permanent home. International adoption should be used with caution as it is important to keep children as close to their linguistic, ethnic and cultural backgrounds as possible (see UN 2009; EveryChild 2009a).

## How decisions about children's care are made

In Malawi and India families collectively make decisions about who becomes a caregiver, where a parent has died or is unable to provide care. Statutory services (social workers) are rarely involved. In India, there was clear consensus from informants that within families it is generally the father who decides where children live. This is in line with the patriarchal structure of Indian society where women and children are not allowed to participate and generally have little opportunity to assert themselves. In female-headed households, it is generally the mother who takes decisions on their child's living situation. Where both parents have died, it is commonly the grandparents who decide where children live. In Malawi, the research indicated that women tended to be the decision-makers within the house about care.

In Ukraine, the situation is very different as courts often make decisions about children's care. EveryChild staff in Ukraine have noted that these decisions are rarely made on the basis of proper assessments of children's care needs, and commonly lead to a deprivation of parental rights and children being placed in residential care. This is slowly changing and there are some efforts to give parents more choices, for example to reduce the number of mothers who give up their newborn babies for adoption or state care through prevention services (early intervention, consultations) and mother and baby units.

The limited engagement of social services in decisions-making in India and Malawi in particular partially reflects the extent to which care is kept within families and communities, with limited recourse to external structures or assistance. However, it also reflects the limited availability of social services to monitor and assess children's care and protection needs. In Malawi for example, there is only one statutory social worker for the whole of Bulala district, located 180km away from the project site. In the country as a whole, only a third of the Department of Child Development's professional

staff allocation is filled and these people have responsibility for an enormous range of tasks (Parry-Williams 2007). In India, the involvement of statutory social services in decisions about children's care in the research site is also extremely minimal.

The research in all three countries suggests that children have limited influence in the decisions around their lives, and both children and adults confirmed that children are primarily excluded from the decisions around where they live.

The lack of involvement of children in decision-making is in contradiction with both the UN CRC and the UN Guidelines on Alternative Care, both of which state that children should be involved in decisions which affect them. The UN guidelines call for decisions about children's care to:

■ **...involve the full consultation of the child, according to his/ her evolving capacities.** ■  
(UN 2009, Art 56)

## Restricted care choices for children affected by HIV?

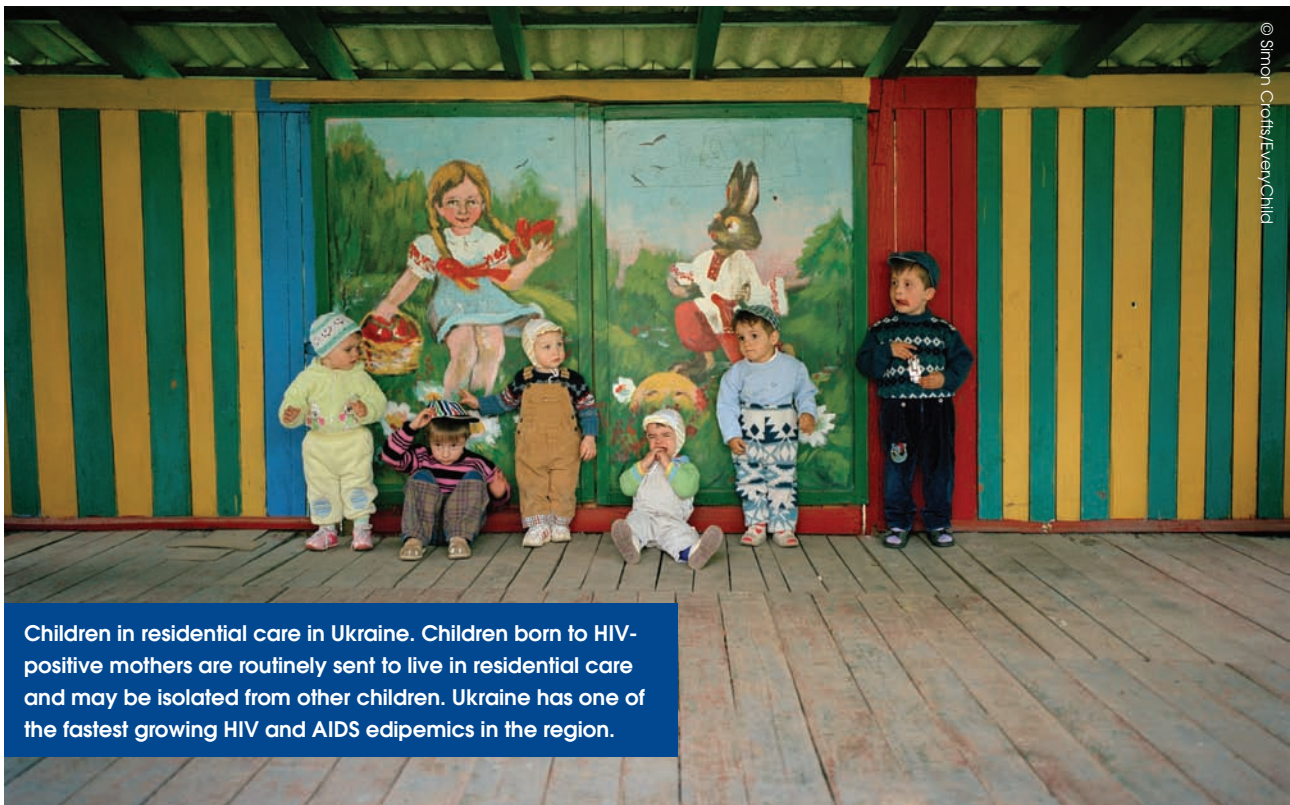
### HIV leading to more children outside of parental care?

Of the three countries included in this research, there is only statistical evidence on the number of HIV-affected children outside of parental care in Ukraine. Although the national percentage of children in Ukraine living without parental care is currently 1.26%, national data suggests that 9% of children registered in HIV and AIDS centres are outside of parental care. The research sites found even higher percentages of HIV-affected children out of parental care, with around 21% of children registered in centres in Kyiv outside of parental care and over one third of the children registered in Bila Tserkva HIV centre outside of parental care.<sup>8</sup>

Despite the lack of statistical evidence in India and Malawi, there is evidence to suggest that, in common with Ukraine, several factors can make HIV-affected children more vulnerable to losing parental care than other groups.

<sup>8</sup> It should be noted that these figures do not represent the complete picture as they cover only children registered in HIV and AIDS centres, and as stated above, these centres are too small in number to provide support to all infected children in Ukraine. It may also be the case that children in state care are more likely to be systematically registered in these centres than children who are in parental care.





First, HIV makes children more vulnerable to a loss of parental care due to parental death. In Malawi, 3% of children have lost both parents, many of them to HIV related illness (NAC 2010). In India and Ukraine, the number of children who have lost both parents to HIV related illness is much lower owing to lower prevalence rates but is still significant. In Ukraine, there are projected to be 42,000 children who have lost both parents to HIV related illness by 2014.

In both Malawi and India it was reported that the death of one parent from HIV can also increase vulnerability to a loss of parental care. In both countries, participants reported that it is common for fathers who have lost their wives to either remarry quickly, or to send their children to live with grandparents, as fathers are not seen as capable of caring for their own children alone. Many research participants stated that such remarriages often lead to parental separation as step-mothers often mistreat their step-children, creating conflict and tension in the home and leading to children being sent, or running away, to live with grandparents.

This trend was contradicted by some fathers who are looking after their children alone. For example, one father included in the research

in India described how he has cared for his children since his wife's death. In both India and Malawi, it was reported that when fathers die, women are usually expected to continue to care for their own children. In Ukraine the almost total absence of male figures in the home was stark and indicates the extremely low levels of male involvement in parenting.

Evidence of links between a loss of one parent, particularly a mother, leading to a loss of parental care is significant as large numbers of children in the countries included in the research, and globally, have lost a parent to HIV related illness. In Malawi 9% of children have lost at least one parent, many of them to HIV-related illness (NAC 2010). In India, at least half a million children have lost at least one parent to HIV related illness (UNICEF 2007). In Ukraine, by 2014 there will be 63-127,000 children who have lost one parent to HIV related illness (World Bank and International HIV/AIDS Alliance 2006). In Africa, there are an estimated 26 million children without mothers, with HIV as a substantial cause. In all three countries, the rolling out of ART will eventually reduce the number of children orphaned by HIV related illness, though, as shown below, there is still some way to go until



all of those in need of these drugs are able to fully access them.

Second, prolonged periods of sickness leading to a loss of parental care were mentioned in both the majority of focus group discussions and in several interviews with households containing either HIV-positive parents and/or extended family carers in Malawi. These periods of ill-health could lead to temporary or long-term separation from parents depending on the nature of the illness. As with parental death, lack of access to treatment for HIV clearly is a significant factor in this case.

Third, in Ukraine participants spoke of discrimination against mothers living with HIV leading to the abandonment of newborn babies. In the past, HIV-positive mothers were actively encouraged to abandon their babies, with many research participants recounting experiences from the 1990s when hospital staff and others encouraged them to give up their babies:

🗨️ **In the late 1990s when I was pregnant a doctor in a hospital after (HIV) diagnosis asked me if I have a house, car and dacha (farm). Then she explained that if I sell all these my child could live for 3 days. They told me that I won't bear it, ..... and insisted on an abortion, they thought I was crazy (to have the baby).** 🗨️ (HIV-positive mother of HIV-positive child, Kyiv, Ukraine)

The research found differing views about whether such child abandonment on the ground of HIV is still encouraged. As shown below, high levels of discrimination by health care providers does continue to exist in Ukraine, suggesting that this may still be a cause for concern. However, some experts interviewed in this research argued that this situation has changed, with many arguing that such discrimination no longer occurs. It is also important to note that whilst medical staff may learn of the mother's status during delivery and encourage child abandonment, mothers with older children would not automatically have to reveal status in care proceedings. It was pointed out that in proceedings when parents are being deprived of their parental rights, HIV status does not have to be revealed and is rarely discussed, suggesting that discrimination against HIV-

positive parents by social workers and others involved in such proceedings is not responsible for higher rates of a loss of parental care.

Fourth, the research suggest that in addition to more direct links between HIV and a loss of parental care, there may be more indirect linkages, with HIV exacerbating factors that commonly place children at greater risk of losing parental care. Global research shows that a loss of parental care is often caused by poverty or irregular incomes and conflict, violence and abuse in the home, risk factors confirmed by several of those participating in this research (see EveryChild 2009a/b). As shown below, HIV can have an impact on both poverty and stress and conflict in the home, including gender based-violence.

Despite this evidence of possible linkages between HIV and a loss of parental care, the lack of statistical evidence from India and Malawi makes it hard to draw firm conclusions about the extent to which HIV leads to a loss of parental care before the death of both parents. As shown below, it is also the case that many parents living with HIV continue to care for their children and do so well. Indeed, evidence from Malawi in particular suggests that in some instances, HIV may actually keep families together, as children can offer much needed practical and moral support to sick parents.

### **HIV preventing children from being cared for in extended families and increasing the use of residential care**

The research suggests that whilst many extended family members are willing to care for children affected by HIV, in some cases, HIV can limit the availability of this care option, pushing some children into residential care. In India it was agreed by the vast majority of participants that relatives, primarily aunts, uncles and siblings, generally do not offer to look after HIV-positive children who have been orphaned. This is mainly due to the stigma associated with being HIV-positive and to a lack of knowledge about how HIV infection occurs, with commonly held beliefs that HIV-positive children will infect other children in the household. Children who cannot be cared for by extended families are generally placed in residential care.

In Malawi, most children without parental care in the research site are taken in by extended family members. However, in a small number of cases HIV-positive parents reported keeping children with them, even when incapacitated or struggling with extreme poverty, because there are no extended family members willing to care for them. As shown below, the research also shows how hard many extended family members find providing for the children in their care as many of these extended families have limited resources. In some cases, this has led to pressure on children to either marry early or migrate to work on tobacco plantations in order to reduce the financial pressure on the family. The research with children in residential care suggests a pattern with most of the children spoken to having come from extended families rather than directly from parental care. However, numbers were too small to draw firm conclusions. These findings reflect wider evidence which shows that despite many claims that extended families are unable to absorb the large number of children orphaned by HIV related illness, extended families are currently able to house the majority of children outside of parental care in the region. However, without further support for families, this situation may change (JLICA 2009).

In Ukraine, the research suggests that HIV-positive children are much less likely to be in extended family care, and much more likely to be in residential care than children in the general population. Recent figures from the research site and from a study carried out in Southern Ukraine (Komarova 2008) support findings that a disproportionately small number of HIV-positive children are in guardianship as compared to children in the general population. It was hard to fully explore reasons for these trends due to the small sample sizes in the research, and they may be due to discrimination or to the broader social problems facing families affected by HIV.

Global research suggests that HIV-affected children may be more likely to be rejected by extended families and placed in residential care if HIV is associated with activities that are seen to be immoral and / or illegal, especially injecting drug use and sex work (UNICEF 2010).

Evidence to suggest that HIV may increase the likelihood of children being placed in residential care is partially supported by evidence to suggest higher than average HIV prevalence rates amongst children in residential care in several countries, including South Africa (Meintjes et al 2007), Brazil (Sherr 2010) and Vietnam (International Social Services 2009). However, further research is needed before the exact nature of this relationship is understood. HIV may directly lead to entry into residential care due to parental death or as a means of accessing health care and nutrition for HIV-positive children, or be a contributing factor, associated with the poverty or abuse that often pushes children into residential care. HIV could also be an outcome of the poverty and abuse that leads to children entering residential care.

In addition to HIV having an impact on decisions about individual children's entry into residential care, it should also be noted that in Sub-Saharan African in particular, HIV may have a broader effect on child care provision in general. The growth in the number of children without parental care in the region has led to a rapid expansion in residential care in an attempt to respond to the 'orphan crisis.' These facilities take on many different forms, including large and small-scale residential care, with varying degrees of quality and regulation (Meintjes et al 2007; UNICEF 2008a; FHI 2010). This growth has not been matched by increased support to extended families, or wider use of foster care or national adoption (see UNICEF 2008a; FHI 2010). Research suggests that the existence of such facilities can act as a magnet, encouraging poor families to place children in such facilities in the belief that they will be better cared for (Tolfree 2003). Thus, the very existence of residential care facilities may shift the balance away from family-based care towards alternative forms of care in some communities.

### **HIV restricting choices between different residential care facilities**

Research in India and Ukraine suggests that being HIV-positive can limit choices between different residential care facilities. In the research area in India, the residential care facilities reviewed have set requirements

outlining which children can and cannot enter their facilities. Primarily children's HIV status, gender and caste influence the decision of whether they can be admitted and the type and location of residential care they end up in. Only two of a number of NGO 'orphanages' in the area accept children infected by HIV in segregated facilities. Other private facilities do not include children who are HIV-positive on the grounds that they do not have the sufficient medical facilities, or through unfounded fears that HIV-positive children may infect others. There are no government-run residential care facilities for children without parental care, only school hostels, and these do not knowingly admit HIV-positive children. There is an 'unofficial' government policy in the area that HIV-positive children should be segregated.

### Who wants to have an HIV kid? (NGO children's home staff member, India)

In Ukraine, the research suggests that HIV-positive children tend to be concentrated in particular residential care facilities, often specialised homes which largely care for children with disabilities. In one instance, an HIV-positive child remained in a home for younger children as facilities for older children were not seen to be able to offer a high enough standard of medical care. As with India, providing proper medical care is used as a justification for segregating HIV-positive children in this way.

As argued by several of the stakeholders interviewed for this research, limiting choices of residential care facilities on the grounds of HIV status is both unnecessary and potentially damaging. HIV-positive children can be cared for by families and care workers with some training and support, but without specialist medical knowledge. Concentrating children in particular facilities can mean that children live far away from families and in care homes not best suited to their other needs. It could also further enhance the stigma and segregation experienced by those affected by HIV.

### HIV preventing access to foster care and adoption

In Malawi and India, foster care and adoption services are virtually non-existent, particularly

in the areas in which the research took place, making it hard to understand the impact of HIV on children's access to these forms of alternative care. In Ukraine, adoption and foster care services do exist, but these are options rarely open to HIV-positive children. It is extremely rare for HIV-positive children to be adopted and there are only five foster families caring for 12 HIV-positive children in the whole of Ukraine. Experts interviewed for this research suggest that this is in part due to the general stigma and discrimination associated with HIV. Experts also pointed out that the fact that HIV-positive children are labelled as disabled can prevent adoption, fostering and guardianship as it is a requirement that such children have their own separate rooms, which makes it hard for some poorer families to accommodate them. Some efforts have been made by NGOs to persuade prospective foster parents to foster HIV-positive children, with some success. However, information on HIV and AIDS is not routinely provided in foster parent training, and these efforts are not reaching a substantial number of foster carers.

## 3.2 Support needs for families affected by HIV

In this section of the report, evidence is provided on the support needs for families affected by HIV in order to ensure that families can stay together, and children are properly cared for. It is demonstrated that when considering family-support needs, it is essential to recognise that families take on many different forms, with varying support needs. Children living with both parents, with step-parents, in single parent households, and with grandparents, aunts, uncles and siblings all have very different experiences.

### Impacts of HIV on income generation and poverty

In all three countries, the research findings highlighted the substantial, practical challenges faced by families with an HIV-positive caregiver. Poverty remains the key challenge faced by families included in the research, a key reason

why children are separated from parents. Globally, research suggests that HIV does not in itself increase the likelihood of poverty, with other factors as more significant causes (see for example Hosegood 2008). In all three countries, sample sizes makes it hard to draw any general conclusions about the likelihood of households affected by HIV being more likely to be poor than others. However, many research participants felt that living with HIV did affect their ability to provide for their families.

In Malawi and India there were indications that HIV-related discrimination reduced access to paid employment. In India, men described the difficulties of starting a business, of not being allowed to work in specific jobs and being avoided by potential employers due to their HIV status.

🗨️ **...people not living with HIV have more money. (When you are HIV-positive) Hard work and money it is reduced. We are unable to work.** 🗨️ (HIV-positive father, India)

🗨️ **I almost cry when I see that she (her daughter) lacks the good things which her friends have...she sometimes says to me 'mum, why did you get this HIV disease, look, now you can't even build us a home. Look, now you can't even do enough work to earn money.** 🗨️ (HIV-positive mother, Malawi)

Parents also reported that regular ill-health makes it harder to find work. Both men and women in Malawi and India confirmed that once they have work, they are unable to commit to regular work attendance because of general weakness and regular ill-health as a result of being HIV-positive. All of the HIV-positive adult participants in India confirmed that they are unable to commit to ongoing work and have irregular daily wages, rather than a consistent monthly wage. Several reported that they could only work if their HIV status was not known. Whilst quite a few parents in Malawi reported being generally well, largely because of ART, most of the 49 HIV-positive parents who took part in the research report not being able to work to their full capacity on a daily basis and/ or periods when they could not work at all. The time needed to access HIV-related health care makes it harder to maintain

regular employment. The general ill-health was especially harmful in labour-intensive jobs. Regular ill-health also changes the nature of work that can be undertaken and this, in itself, can make it harder on the family. Some parents included in this research spoke of struggling to do the farm work they used to do, and some parents expressed feelings of guilt and inadequacy at this change.

Few parents included in the research in Ukraine were in paid employment as most were single mothers with children under three, and were still eligible for state grants, so impacts of HIV on employment were less likely to be noticed here. This issue is likely to increase in significance as children get older and was already a cause of concern for some participants:

🗨️ **I found a job of a baby-sitter when I didn't know about my status. And now parents ask me to sit with their baby from time to time, when they are on business trip. But if they knew, they would refuse my services.** 🗨️ (HIV-positive mother, Poltava, Ukraine)

In Ukraine, as in many other parts of the world, HIV-affected families often face a complex range of challenges, which are linked to poverty and other problems faced. Research shows that 80% of families with HIV-positive children are below the official poverty line, and in many cases, parents are addicted to drugs or alcohol and/ or have been imprisoned (UNDP 2008). Whilst the epidemic has moved from being a problem primarily affecting intravenous drug users and commercial sex workers to impacting on the wider community, it is still the case that there are many HIV-positive families also affected by drug use or commercial sex work. According to experts interviewed for this report, many families affected by HIV are headed by women.

🗨️ **Speaking about Kyiv today the majority of infected children live with biological parents. Usually with the mother, rarely in full family, sometimes they have - a 'visiting' father, meaning women think of themselves as married, but it's not true. In very rare cases they live with a stepfather.** 🗨️ (from the in-depth interview with representative of AUN PLWHA)



Families used a variety of strategies to respond to poverty. In Malawi, HIV-positive parents struggling to provide food and shelter for their children report that they take on less strenuous jobs such as small-scale market gardening, beer brewing and selling, or mat-making. In Malawi, in particular, there were indications of family separation being a crucial part of livelihood strategies, in particular a loss of parental care through early marriage or child labour as survival strategies. In India, one child expressed fear of bonded labour as a result of his parent's illness:

▲▲ **For a loan they (parents) will sell us.** ▲▲  
(Boy affected by HIV, India)

Social protection through, for example, cash transfers or income generation programmes, potentially offers families incapacitated or discriminated against as a result of HIV a means of maintaining or enhancing income levels. The availability and content of social protection varied greatly between the three countries. In Malawi, a national cash transfer programme is being piloted in seven districts targeted at ultra-poor and labour-constrained households. There are also income generation schemes and a school feeding and bursary programme for vulnerable children run by NGOs and community-based organisations (CBOs). Whilst some research participants do benefit from the NGO and CBO-run programmes, the national cash transfer scheme had not been rolled out in the research area at the time of the research. Most participants also felt strongly that any existing social protection they were receiving was inadequate and the vast majority identified social protection as a key support need to better enable families to care for children.

In India, there is a national old age pension for the elderly plus other disadvantaged groups, such as 'deserted wives' or those with disabilities as well, as and widows, including those who have been widowed by HIV. The National Rural Employment Guarantee Scheme (NREGS) assures each rural household 100 days of unskilled wage labour per year at a certain, locally relevant wage. The central government's Centrally Sponsored Scheme (CSS) establishes educational hostels to encourage scheduled caste and scheduled tribe children to pursue

higher education. In addition, there are a range of nutrition and cash-based interventions. HIV-affected families receive preferential treatment under some government and NGO-run social protection schemes but some participants reported being concerned about accessing such support:

▲▲ **We do not want any support because of fear that many will come to know about our infection.** ▲▲ (HIV-positive father, India)

Ukraine has a wide range of social assistance grants, although many of these require registration and – in the case of HIV-specific entitlements – disclosure of HIV status and often registration as a disabled person. There are a range of benefits that do not rely on HIV status, including a state allowance for single mothers and grants to foster carers or adoptive parents. In Ukraine both HIV-positive parents and those caring for children affected by HIV said that the benefits they receive are only enough to buy food and basic items, which was a concern in particular for those caring for HIV-positive children.

▲▲ **My child benefits are not enough to use vitamins, to drink juice, to buy medicines.. I feel that I have to eat vitamins myself but I can't afford it. My child has relatively good nutrition, especially the younger one. My main funds I spend on her... I spend 50 UAH (around \$8) per day, including 30 UAH only for my younger daughter. My elder daughter gets almost nothing.** ▲▲

(Single HIV-positive mother of two children, Poltava, Ukraine. Her first child is HIV-negative and her newborn baby has not had HIV test results confirmed)

Despite availability of some schemes specifically for HIV-positive parents, the research found that few HIV-positive caregivers were accessing benefits that they are entitled to as, like in India, many did not want to reveal their status.

An additional problem noted in Ukraine is that access to state grants for HIV-positive children is largely linked to being classified as 'disabled', and this process is time-consuming, bureaucratic and requires revealing their own or their child's status to a range of officials. Some

participants also reported not wanting to give the children in their care the negative label of being 'disabled.'

🗨️ **My grandson says to me, I hear from other people that I'm disabled. But I am not, am I right? And I assure him that he is not.** 🗨️

(Carer of three children, one of whom is HIV-positive, Bila Tserkva, Ukraine)

This challenges the nature of the way in which HIV is classified because someone with HIV can be healthy and productive, and not necessarily fulfilling disability criteria. It of course also raises bigger questions about discrimination against disability itself.

The findings endorse global evidence that demonstrates that 'AIDS exceptionalism' (singling out HIV as a response, rather than strengthening a system to address poverty or lack of services) is inappropriate (summarised, for example, in JLICA, 2009). Self-exclusion because of perceived discrimination is a major challenge, and any form of social protection scheme that requires an open statement of having HIV is unlikely to be taken up fully whilst there remains discrimination from family, community and state service providers. However, the research does show that households affected by HIV have some HIV-specific vulnerabilities that need to be addressed if the household is to be supported out of poverty. This is particularly relevant when looking at possible responses, such as social protection interventions or delivery of HIV-related treatment with a family focus.

The links between poverty, HIV and a loss of parental care, and the widespread use of extended family care to care for children affected by HIV, suggest that the relationship between social protection and child protection and care need to be considered. A review of the global literature suggests that these linkages are poorly understood, and often not considered in the design of social protection schemes. This can lead to some programmes either missing out the most vulnerable or inadvertently making matters worse by actively encouraging family separation. In Ukraine, for example, it has been observed that higher payments to guardians can push children out

of parental and into extended family care (EveryChild 2010; Giese 2007).

## Accessing health care

As noted above, the increased availability of ART means that many HIV-positive parents and other carers should now expect to remain healthy and alive for longer. However, in all three countries included in this research, evidence suggests that many of those who might benefit from ART are not receiving these drugs.

In Malawi, significant progress has been made in the availability of ART in recent years, but many of those with HIV in rural areas still have to travel significant distances to obtain the drugs they need (NAC 2009). In the research site, the local health clinic does not have a fridge, so HIV-positive patients on ART have to travel to the hospital every month – a 45km journey that takes one and half hours by car, costs around MK1000 (\$6.7) return, or a walk of up to two days.

The regular travel for health care additionally generates problems with child care, especially for single-parent families. One mother, who was left by her husband when he discovered she was HIV-positive, described having to repeatedly persuade friends and relatives to travel with her to hospital to help with her young children whilst she got her drugs. This woman already faces many agonising decisions about how best to deploy her limited resources in order to care for her children:

🗨️ **I am afraid that I will pass on HIV to my baby because I was supposed to stop breastfeeding at six months, but now look, they are 10 months old and I am still breastfeeding them. If I stop, where will I get the milk? And if I stop, they will get malnutrition.** 🗨️ (HIV-positive mother, Malawi)

In India, although NGO staff reported that the local ART centre offers a good service and works in collaboration with local NGOs, those affected by HIV reported several challenges in accessing medical care, including limited availability of services, delays in receiving medicines and having to travel long distances to receive ART.



In rural areas in Malawi, HIV-positive parents have to travel long distances, sometimes for days at a time, to gain access to ART.

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### ▮▮ No ART tablets are given during holidays. ▮▮ (HIV-positive girl)

Participants also mentioned that as they have to travel long distances and it takes time to access ART it is hard to keep their status from bosses or teachers. As a result many adults and children alike reported that they change if, when and how they access services so as to keep their status secret. This means they either receive less support than medically necessary or do not access any:

### ▮▮ When others speak about my infection I felt unhappy. When I apply to leave to get ART tablet my teacher used to question me. ▮▮ (HIV-positive girl)

A couple of research participants in India also mentioned discrimination by medical staff.

In Ukraine, it is estimated that of the 23,297 people who could benefit from ART, just under one third are receiving them.<sup>9</sup> The majority of HIV-positive caregivers and those caring for HIV-positive children also reported discrimination by medical staff in hospital and clinics, with the exception of dedicated HIV treatment centres. Staff were

reported to be not properly attentive, isolating them from other patients, or actually refusing to treat them. In some instances, staff were reported to have breached confidentiality about the informant's HIV status and revealed it to others.

### ▮▮ My first child is nine years old, he is HIV-infected. When I went to the polyclinics for the first time with him, nobody let me undress him or put our coats in an ordinary cloakroom. I had to enter the building by a separate entrance; I had to leave my push-chair outside - where it was snowing and cold. Doctors examined us outside. When I left by this separate entrance, all the people in the queue were staring at me and my child, as the information desk on the front door said with capital letters 'ISOLATOR'. ▮▮ (HIV-positive mother of two children, Poltava, Ukraine)

### ▮▮ Doctor came to examine my grandson - all these white coats, three pairs of gloves... It was a nightmare. The doctor entered a ward for 20 children and asked 'who is HIV-positive here?' ▮▮ (Carer of HIV-positive child, Kyiv, Ukraine)

<sup>9</sup> Ministry of Health (Ukraine) (2010). HIV infection in Ukraine: Information bulletin no. 33. Kyiv, Ukraine. Ministry of Health (Ukraine) p. 13. Note that these figures are calculated only for PLWHA who are registered in System of Monitoring of Treatment of Ukrainian HIV/AIDS Centre. According to national data indicators 48% adults and 100% of children with progressive HIV-infection receive ART. Ibidem, p.26



## Accessing education and other basic services

Child participants mentioned that having to care for their sick parents on a regular basis was an obstacle to their access to education, and girls were mentioned as being more likely to be withdrawn from school. Reduced access to education was particularly the case for children who were themselves HIV-positive. In India and Ukraine, children described instances of discrimination in school:

▲▲ **All students sit on the bench but I am only allowed to sit on the floor.** ▲▲

(HIV-positive boy, India)

In India, children described how they have been asked to leave classrooms when they cough. In one case a girl explained that she had discontinued with her schooling as a result of the bullying and discrimination. And at one school in Theni six affected children have been excluded on the grounds of their status while in other schools children have been asked to go on long leave:

▲▲ **Go and get your child well and (then) come back to school.** ▲▲

(Statement made by a teacher reported by an HIV-positive mother, India)

Over half of the HIV-positive children spoken to keep their status secret in schools, even though being HIV-positive means they are applicable to receive school books, uniforms and other educational materials from NGO or state services. The reason reported was that collection of such benefits requires a teacher's signature which would potentially give away the child's HIV status. This further supports arguments made above for not targeting benefits on the grounds of HIV status.

Access to shelter and water was also an issue for some:

▲▲ **We were in the rented house. After knowing about our infection we are in the goat's hut.** ▲▲

(Boy affected by AIDS living with extended family, India)

## Stress and conflict in the home

Across all three research sites, children and caregivers reported increased stress and tension in the home as a result of HIV. This included both when children were living with their HIV-positive parents, as well as when living with other family caregivers. Emotional stress was reported as making it harder for parents or other caregivers to provide love and protective care. Problems occur within the home, either because of the stress that HIV-positive parents or elderly caregivers are under, or because of changes in caregiver. HIV-positive parents, children and extended family carers all reported stress, anxiety and/ or depression as a result of being HIV-positive, with this hampering relationships in some cases:

▲▲ **They are always afraid to die.** ▲▲

(Boy in extended family care talking about the problems that HIV-positive parents face, Malawi)

▲▲ **HIV-positive people lack peace - we can't chat with our children.** ▲▲

(HIV-positive mother, Malawi)

▲▲ **The most awful thing is that I have to hide the status from everyone and everywhere. People don't know anything, it's the most terrifying. Youth can adapt, but people of my age they don't understand. I am afraid to bring my grandson to school. Sometimes I have insomnia because of this psychological tension.** ▲▲

(Carer of HIV-positive child, Kyiv, Ukraine)

In Malawi, parents who had lost a partner to HIV related illness spoke of the stress of bringing up children alone and a loss of guidance and support from their husband or wife. In a couple of cases in Malawi, parents reported conflict in the home caused by HIV, including abandonment by a partner. Several women reported finding it hard to discipline their children without their fathers around, and a few men admitted finding it hard to cook and care for children when mothers were absent.

▲▲ **Even my own son is a drunkard. He makes me cry. He lost his father. I don't even know what to do with him.** ▲▲

(Single mother, Malawi)



The stresses caused by being HIV-positive, and the strains that this can place on family life, was recognised by parents and caregivers as having an impact on children. One volunteer engaged in the Malawi Network of People Living with HIV (NAPHAM) spoke of depression and anxiety amongst such children, leading to alcohol abuse for boys and girls seeking attention from boyfriends with consequent early pregnancies.

■ ■ **They (children who have lost parents) grow up sad and depressed and as a result become drunkards in later life.** ■ ■

(NAPHAM Bulala Branch secretary, Malawi)

In many cases widowed parents, especially fathers, attempt to overcome parenting problems by entering new families, but in all three countries children and other family members referred repeatedly to the challenges this can create for children. Adult and child participants spoke of step father and mothers treating the child badly, often culminating in children being sent away to live with grandparents.

In the global literature, there is also growing recognition that stress caused by HIV can impact on children both before and after parental death. Recent research shows that children living with HIV-positive primary caregivers face a significant amount of psychosocial stress and increased poverty prior to the death of the HIV-positive caregiver (summarised in JLICA, 2009). A recent research study from South Africa is one of the first to demonstrate that children with HIV-positive sick carers have as much psychological distress as children who are already 'AIDS-orphaned', and greater than children caring for carers who are sick or have died of other causes. The preliminary findings show long-term psychological distress (up to four years after a parent's death), major education problems due to caring responsibilities, poverty, and worries. They also experience more bullying, emotional abuse, physical abuse and transactional sexual exploitation (Cluver et al, 2010b).

Although caregivers, both parents and extended family, were clear that they provide love, care and support and that the primary assistance needed is on the practical aspects,

in Ukraine and Malawi, parents and caregivers valued the parenting and psychosocial support provided by NGOs, and sometimes from concerned and supportive neighbours and HIV specialist agencies. Such support is important not only for improving the relationships and reducing stress in the home, but also for decreasing rates of family separation. Stress and conflict in the family have been shown to be major factors which place children at risk of losing parental care (see EveryChild 2009a). For example, it is already known that high levels of stress in the household can lead to children running away from home (UNICEF, 2010; RELAF, 2010; StreetAction, 2010). The evidence presented on step-families further suggests that parenting support, and perhaps some form of mediation, is essential when parents remarry to keep children within parental care.

## Isolation from communities

Stress and conflict in the home, poverty, and limited access to services are likely to be exacerbated by discrimination in the wider community. The evidence shows that children affected by HIV are stigmatised and not included equally by other children and / or neighbours purely due to their own or their parent's status. Neighbours and relatives often treat such children differently, they are shunned, shouted at, ignored and excluded from family events. The India and Ukraine research demonstrate low levels of overall knowledge about HIV, and fear about its potential implications on others. In addition, a disease that is associated with sexual behaviour and injecting drug use leads to very high levels of blame being placed on people living with HIV. At times such accusations also imply a level of immorality (such as promiscuity) that, according to a number of community members in India, deserves to be punished.

■ ■ **Many students will say ....that his father dies of HIV so do not have friendship with him.** ■ ■

(HIV-positive father, India)

The India research, in particular, shows how girls and boys are direct recipients of abuse and violence. Girls and boys affected by HIV mentioned how they are criticised, avoided,

not spoken to and not included in play. One HIV-positive mother in India described how she and her children were separated from the rest of the family by a wall constructed in the middle of the house. It was reported to move beyond emotional abuse to active violence in several cases.

All participants across the three research sites had frequent and painful stories of discrimination. However, it should be noted that in all three countries there were many stories of acceptance and support. In both Malawi and India discrimination was reported to be reducing. This is backed up by other evidence. One research study in Malawi found that although discrimination against orphans was widely reported, when families and neighbours were asked to reflect in-depth, there were fewer cases of known discrimination against non-biological children than expected (Peters, Kambewa & Walker, 2008). Children report many positive experiences, including close emotional relationships and a sense of confidence for the future. This includes evidence that children who are living with non-biological caregivers manage to develop their own networks of support and a real sense of belonging within their new households and communities (Clacherty, 2008; Evans, 2010, Skovdal, 2010).

## **The burden on women and particular challenges faced by women**

In India and Ukraine, there were substantially higher numbers of female caregivers than male. In Malawi, there was more of a gender balance, although the findings do not sufficiently indicate who carried out the household caring responsibilities to draw conclusions. As noted above, in India and Malawi, fathers are likely to remarry immediately following the death of a partner, or send children to live with extended family members. Women who have lost their husbands are more likely to continue to care for their children alone than men, and grandmothers were reported to play a greater role in children's care than grandfathers. In

general, it is reasonable to assume that women carry more of the direct nurturing responsibility. This evidence reflects one of the common themes running through the literature on HIV-affected children is the insufficient engagement of the father, or father figure (Hosegood & Madhavan, 2010).

It should be noted that, of course, not all men fail to contribute to care giving, and there were participants in the research who did demonstrate the father's and male caregivers' commitment to the children in their family. The research did find fathers who were struggling to provide for their children and boys who were playing a significant caring role. This should be acknowledged and further supported.

The general lack of male involvement is a cause for concern as women caregivers face particular challenges. In India and Ukraine, in particular, several factors place women at much greater risk of poverty but also of abuse, violence or exploitation. Much of this relates to community-based or traditional legal issues. In India, in addition to existing gender discrimination in employment, widowed mothers who are HIV-positive are generally not accepted by their late husband's or their own family and so in many cases are denied property.<sup>10</sup> Renting property is also a challenge due to the stigma and cost implications described above. Women described psychological impacts of being widowed and/or outcasts from society such as low self-esteem and poor confidence, and outlined related health implications. This directly impacts their income earning capacity. Women spoke clearly of their struggle to balance their illness, earn an income and care for their children:

■ ■ **For everybody father used to buy notebooks for their children. But for me in the absence of father my mother finds it difficult.** ■ ■

(Girl affected by AIDS living with HIV-positive mother, India)

■ ■ **I cannot provide good education and care.** ■ ■ (HIV-positive mother, India)

<sup>10</sup> This may reflect wider discrimination facing widows in India.

The research findings are significant given that the Indian National AIDS Control Organisation (NACO) find that up to a third of households affected by HIV or AIDS are headed by widows who face double stigma and often cannot earn an income, or send their children to school. As a result many resort to sex work. This in turn places the woman, as well as her children, at risk of violence and may lead to a greater chance of separation (NACO et al 2007).

Gender-based violence and violence against children within the family was referred to in the research. Notably in Ukraine, several informants linked lack of disclosure to fear of violence from male partners.

🗨️ **I am afraid to tell him that I'm HIV-positive, he will beat me...I even don't dare to think what he will do to me and my child.** 🗨️  
(HIV-positive woman, Poltava, Ukraine)

A lack of male involvement may increase risks of family separation. There is evidence that women who choose to put their children into care often lack the support of the father, especially in Central and Eastern Europe/ Commonwealth of Independent States (CEE/CIS) (UNICEF, 2010). One review in Uganda found that fathers of children with HIV-positive mothers had significant increased paternal absence and disengagement than families with HIV-negative mothers (cited in Sherr, 2010). As noted above, gender-based violence, especially violence by partners, may be grounds for women feeling unable to care for their child and is often also grounds for children leaving home. As noted by Hosegood and Madhavan (2010) seeking information about father involvement is an important tool for identifying particularly at risk families, or for supporting men who are trying to fulfil their parental responsibilities.

Although not fully explored by this research, the challenges faced by women may be further exacerbated by inheritance rights, which often favour men and boys, and can leave women with little if their husbands die.

## Caring for an HIV-positive child

As noted above, a child's HIV status does affect the willingness of some extended family

members to provide care. There were also some rare cases of discrimination from parents against HIV-positive children. One HIV-positive girl in India described how her mother treats her differently to her brothers and sisters and beats her. However, apart from these few cases, in the main those children who are infected are not treated differently by their parents or carers.

🗨️ **We never differentiate our own children. All are our children only.** 🗨️  
(HIV-positive mother, India)

The research also suggests that parents and carers can provide care for HIV-positive children. For example, in India and Ukraine, HIV-positive parents and extended family members caring for HIV-positive children demonstrated good knowledge of HIV, including administration of ART and were committed to providing adequate nutrition for the HIV-positive children in their care. Despite the fact that the findings are small-scale, they are important as they challenge the common perception, held for example by staff interviewed in residential care facilities in Ukraine, that families are incapable of providing quality health care for HIV-positive children. As reported above, this opinion is also common amongst medical staff and has led to them encouraging child abandonment in Ukraine.

Although parents and carers can clearly provide sufficient care for HIV-positive children, caring for such children is not without its challenges - including accessing ART and providing sufficiently nutritious food - problems exacerbated by the inadequate service provision, discrimination and poverty described above which faces many families affected by HIV. In addition to these more practical problems, participants in India described additional anxiety about children's marriage prospects. Of particular concern to the HIV-affected parents and caregivers in India was the longer-term marriage prospects for girls, in a society where financial security is bound up with marriage. For girls who are infected by HIV their chances of getting married decline rapidly, or disappear altogether:

🗨️ **If our child is positive marriage will not take place in her life.** 🗨️  
(HIV-positive father, India)

## Particular issues for children in extended family care

The research suggests that many children living in extended family care are receiving love, care and support. This is reflected by the overwhelming majority view by caregivers and children interviewed in all three countries that their first choice of caregiver, after a parent, is a grandparent. In the research findings in all three countries, extended families commonly see the arrival of a child whose parents has HIV as a positive experience, including those children who are HIV-positive.

For example, in Malawi, many extended family carers, and a few children in extended family care, spoke of these girls and boys establishing good relationships with other children in the household. Some participants spoke of material benefits for children in entering extended family care in terms of receiving food, shelter and clothes. Grandparent carers and children often spoke of the contributions that children, particularly older children, make to the household in terms of housework, farm chores or bringing in an income through paid work. Some grandparents, particularly grandmothers, also hoped for longer-term benefits, with children now in their care providing for them in older age. This finding is backed up by other literature that shows that 'orphans' are often appreciated as much for what they bring to the household in practical terms as they are recognised as a potential additional financial burden (Skovdal, 2010).

Positive feedback from children, parents and extended parents (especially grandparents), is quite often at variance with assumptions from social welfare providers. This is most noticeable in Ukraine where it seems that some practitioners in the state sector assume that children living with elderly and poor family members 'would be better off in care' with access to material benefits.

Despite evidence of the benefits of extended family care, children in extended family care, and extended family carers, do experience problems and challenges. Extended family carers may themselves be HIV-positive, and this

was particularly the case amongst research participants in Malawi. Such carers experience the same problems with discrimination, poverty and access to services as parents affected by HIV.

As noted above, extended family carers are often grandparents as this is the preferred choice of carer. Whilst, as shown above, these grandparents often offer love and support, many struggle to provide financially for the children in their care, particularly in settings such as rural Malawi where many rely on manual labour for survival. Many extended family carers included in the research are female, with the associated discrimination and challenges earning an income described above. Although other evidence shows that many of these families try to provide appropriate care for their children, levels of poverty are extremely high (Hosegood, 2008).

The research suggests that children in aunt, uncle or sibling care may be particularly vulnerable to discrimination within the family, and to sexual, verbal and physical abuse, although by no means do such problems occur in all such households.

A few of the participants in the Malawi research spoke of sexual abuse in extended family care, usually when children were in the care of uncles or brothers-in-law. A church leader and a health worker also both spoke of girls being abused by uncles and brother-in-laws, and of these children being too scared to report such abuse:

🗨️ **These children are frightened they will be killed if they reveal the abuse done to them by uncles or any other relative.** 🗨️ (Male health worker, Malawi)

This health worker reported relatives sending girls to sleep in neighbours' houses when their own homes were too full, and these girls being vulnerable to sexual abuse, and sometimes being forced into prostitution at an early age. Participants in earlier consultations conducted by EveryChild also suggest sexual abuse against girls in extended family care in Bulala:



🗨️ **Usually her (sister's) husband will want to sleep with you as his second wife. In our culture, you can marry your cousin, so if you happen to stay with him, he will start making advances at you to have sex with him. You could become pregnant and drop out of school.** 🗨️

(Girls from Bulala who took part in a previous consultation with EveryChild – see EveryChild 2009a)

In India and Malawi, children spoke of verbal abuse from carers, particularly aunts, uncles and siblings, often in relation to frustration at having to care for an extra child. Children and carers spoke of discrimination against children who are not the biological children of the carer, with these children expected to do more work and given less food than other girls and boys in the household. Such discrimination was particularly reported in aunt and uncle care, perhaps because these carers were most likely to have children of their own living at home than grandparents.

🗨️ **...To care for an orphaned child is a big burden. For instance, when we share food there is a tendency to favour our own children to have bigger shares....these are nephews and nieces and even their surnames are different from ours. They are not part of us.** 🗨️

(Male extended family carers, Malawi)

In India, NGO staff report that extended family carers commonly express concerns about HIV-positive children infecting other children in the household. With discussion and awareness-raising, these fears are often reduced, but lingering doubts may remain and affect relationships in the home.

Evidence in the global literature on levels of discrimination and abuse faced by children in extended family care is mixed and suggests that context is significant. The research in India and Malawi took place in rural areas, and literature elsewhere indicates that there are fewer kinship and social support networks for children in urban areas (Crush et al, 2006).

Although not fully explored by the research in Malawi, India and Ukraine, emerging evidence shows that children living with extended family are particularly vulnerable to exclusion from HIV-related treatment. One piece of research indicates that non-parental caregivers are significantly less likely to know their own HIV status<sup>11</sup> and thus to be able to care for HIV-positive children (Mudzingwa & Reddi, date, cited in Leeper et al, 2010).

11 Lack of appropriate HIV-related prevention and treatment for older people is a significant challenge and is in itself a priority area (HelpAge International, 2008).

# 4 Conclusions and recommendations

The research findings point towards four key conclusions. Firstly, although children affected by HIV should have the same care choices open to them as other children, currently they do not. They are more vulnerable to losing their parents at an early age, often due to inadequate access to ART, and HIV-related ill-health, discrimination, poverty and stress can have indirect impacts on the numbers of children outside of parental care, contributing to the complex range of risk factors which push children away from families. Children affected by HIV, particularly HIV-positive children, may be denied extended family care, access to some residential care facilities, foster care and adoption because of discrimination, or misguided worries about HIV-positive children infecting other children or requiring specialist medical care. In Sub-Saharan Africa in particular, HIV is in part responsible for a changing care landscape, as the growing number of children orphaned by parents dying from HIV related illness is being used as a rationale for the unchecked expansion of many different forms of residential care.

The limiting of children's care choices as a consequence of HIV is unacceptable. The research from the three countries clearly endorses the general global consensus that supporting children in family-based care is generally the best option for the care of children, backed up by appropriate child protection services. HIV is not a special case that requires a different approach to family-based care. Thus, children should be able to stay with parents unless it is in their best interest to be separated. Where this is not possible, it should be recognised that extended families currently care for the vast majority of children outside of parental care in many settings, and offer a positive choice for many children. The research shows that both HIV-positive parents and their children express a

strong desire to stay together, and where this is not possible, many feel that grandparent care offers the next best option. HIV-affected families can also offer good quality care to children affected by HIV, including HIV-positive children, though in some cases they may need some external support.

HIV-affected children outside of family care should be offered the same range of care options as other children. Residential care, particularly large-scale, dormitory-style care, should be used with extreme caution, and decisions about which residential care facilities are used should be based on considerations of a range of children's needs and not just their HIV status. Foster care can offer a positive short-term family-based care option for children, and adoption can be used as a permanent solution for children who are without parental care. Where foster care and adoption are used, efforts should be made to ensure that HIV-affected children are able to access these forms of care in the same way as other children.

Second, families affected by HIV need to be offered more support to care for children and, whilst many of these support needs are similar to the support needs for other vulnerable families, HIV-affected families do face some particular challenges. For example, bouts of ill-health combined with poor access to health care make it particularly hard for HIV-positive carers to earn a regular income. Discrimination against HIV-positive adults prevents access to work or basic services. Discrimination and health worries place an enormous psychological burden on carers and children alike, leading to stress, and in some cases, conflict in the home. Caring for an HIV-positive child can cause particular anxiety and increase the need to access health care services and provide nutritious food for the family. Child

care responsibilities make it especially hard to travel long distance to get necessary medical treatment.

Third, in supporting HIV-affected, and indeed any vulnerable family, it is essential to recognise differences between family types. For example, grandparent carers often offer enormous love and emotional support to children, but may struggle with poverty. Children in aunt, uncle or sibling care may be more likely to suffer from abuse and discrimination than those in grandparent care. Children in step-families are particularly vulnerable to family separation. Women in all kinds of families take on the bulk of responsibility for children's care, and in many instances bring up their own children, and their grandchildren, nieces, nephews or siblings with minimal male support. Some men do struggle against social norms and bring up children alone. In all cases, single-parent/ single-carer households may have particular support needs.

Finally, whilst it is easy to dwell on the challenges faced by parents and families caring for HIV-affected children, it is important to not miss the enormous, and largely successful efforts made by families to provide love, support and basic necessities to children in often extremely challenging circumstances. Any efforts to further support families affected by HIV should build on these successes.

These conclusions point towards several policy recommendations for donors, UN agencies, national governments and NGOs:

### **Children affected by HIV must have the same care choices as other children through:**

- Enabling all children, including HIV-affected children, to remain with parents unless it is in their best interest to live elsewhere through greater support to families (see below).
- Providing financial and other support to extended families, and recognising that support needs are likely to vary by family type.
- Ending the unchecked expansion of residential care, and ensuring that this form of care is used with caution for all children, including those affected by HIV.

- Campaigns to reduce discrimination amongst care providers, and challenge ideas about HIV-positive children requiring specialist medical care or being a risk to other children.

### **Families affected by HIV must have more support to care for children through:**

- Greater social protection provision which reaches particularly vulnerable families, including grandparent and female-headed households. Social protection should not be targeted based on HIV status alone, but should recognise that HIV may increase the vulnerability of families. Social protection must consider and monitor impacts on children's care and protection.
- Increased general access to ART, which recognise the particular challenges faced by parents and carers in accessing drugs and health care.
- Psycho-social support for children and carers.
- Reduced discrimination and increased support to enable all vulnerable families, including those affected by HIV, to access health, education and welfare services.
- Recognising the complex and multiple needs of some HIV-affected families, and providing support to enable drug users and sex workers to care for their children if possible.

### **There must be greater investments in inclusive child protection services, and alternative care providers must recognise the support needs of children affected by HIV through:**

- More investments in state and community-based child protection for all vulnerable children/ families.
- Child protection services that do not discriminate against HIV-affected children, recognise the particular challenges faced by HIV-positive families, and the varying vulnerabilities of children to abuse and neglect in different family types.

- Alternative care providers giving appropriate care and support for HIV-positive children, including medical support, psycho-social support, and support around issues such as a marriage and protecting future or current partners from HIV infection.
- Guidance for all children in alternative care on protecting themselves from HIV infection and preventing the spread of HIV.

**Discrimination on the grounds of gender or HIV status in families and communities must be challenged through:**

- Wider work within communities to increase knowledge and understanding of HIV and reduce discrimination.
- Acknowledging the links between HIV and discrimination against women and girls, and challenging practices which lead to their exploitation and abuse, including early marriage and gender-based violence.

The research also highlights the lack of attention previously paid to the links between children's care choices and HIV by researchers and policy-makers, and the need for further research and gathering of best practice on this important topic. In particular, it is important to more systematically monitor the impacts of discrimination on the grounds of HIV, and indeed due to other factors, such as gender and disability, on children's care choices. Further research is also needed on:

- The links between social and child protection and care to explore means of best supporting vulnerable families, including families affected by HIV, to stay together. This includes exploring impacts of different forms of social protection on a loss of parental care, and impacts of the intra-household dynamics of the distribution of resources in different family types.

- The experience of HIV-affected children in residential care, and HIV-affected children and families in care proceedings.
- Understanding and responding to children's experience of HIV-related stigma, including identifying where stigma increases a child's risk of family separation or reduces access to basic services.
- The extent to which children without parental care can themselves access HIV testing and treatment. This includes children in residential care facilities, children living and working on the streets and children living in extended families.
- The particular needs of adolescent boys and girls without parental care, including their potential vulnerability to HIV infection, through sexual or drug using behaviours. More is needed to understand how to promote resilience in adolescent children and which interventions are most effective for children transitioning out of care.

Ensuring that positive care choices can be made about children affected by HIV requires joined up and co-ordinated action, with those with expertise on HIV-affected communities and those with experience in the fields of child protection and alternative care working closely together. Governments and donors must work to incorporate these recommendations into national and international policies on HIV and on child protection, including national action plans for children affected by HIV.



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# Annex 1:

## Details of research participants

**Table 1: Focus group discussion participants**

	India			Malawi			Ukraine			TOTAL
	Male	Female	Total	Male	Female	Total	Male	Female	Total	
<b>HIV-positive parent</b>	35	37	<b>72</b>	17	32	<b>49</b>	1	14	<b>15</b>	<b>135</b>
<b>HIV-positive children</b>	16	24	<b>40</b>					5	<b>5</b>	<b>45</b>
<b>Children living with HIV-positive parents</b>	16	8	<b>24</b>	8	23	<b>31</b>		2	<b>2</b>	<b>57</b>
<b>Children living with extended family members</b>	8	8	<b>16</b>	21	19	<b>40</b>				<b>56</b>
<b>Grandparents caring for children affected by HIV</b>	8	8	<b>16</b>	18	9	<b>27</b>	1	13	<b>14</b>	<b>57</b>
<b>Other relatives / foster parents caring for children affected by HIV</b>				9	8	<b>17</b>		1	<b>1</b>	<b>18</b>
<b>Adults not affected by HIV (control group)</b>	8	17	<b>25</b>							<b>25</b>
<b>Children living in institutions</b>	5	3	<b>8</b>	17	16	<b>33</b>				<b>41</b>

**Table 2: Category of the households included in the in-depth interviews**

	India	Malawi	Ukraine	TOTAL
Single-headed households with HIV-positive parent	2	7	4	<b>13</b>
Dual headed household with HIV-positive parent(s)	2			<b>2</b>
Household with both HIV-positive parent and grandparent or other relative carer		5		<b>5</b>
Grandparents caring for children affected by HIV	6	3		<b>9</b>
Not affected HIV (control group)	2			<b>2</b>
Other relatives caring for child affected by HIV	4	6	1	<b>11</b>
Child headed household		1		<b>1</b>
<b>Total</b>	<b>16</b>	<b>22</b>	<b>5</b>	

**Table 3: List of key stakeholders involved**

Category of stakeholder	India	Malawi	Ukraine	TOTAL
Community leader, religious representatives and other local representatives	3	2		<b>5</b>
Local community-based organisation / NGO	2		3	<b>5</b>
Representatives of HIV-positive people's organisation	1	1	2	<b>4</b>
Local counsellors and government representatives	1			<b>1</b>
Local service providers (social welfare workers, nurses etc.)	4	2	14	<b>20</b>
District AIDS coordinating bodies	1			<b>1</b>
National policy-makers		5	4	<b>9</b>





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