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Children living with and affected by HIV in residential care

Desk-based research
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Gillian Mann, Siân Long, Emily Delap and Lucy Connell

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This is a working document which will be continually updated. If you have information and evidence to share, or questions on this report, please email: policy@everychild.org.uk



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SUMMARY

In many countries, significant numbers of children are temporarily or permanently cared for in residential care. The exact numbers of boys and girls living in such circumstances is not known, although it is estimated to be at least two million globally, and likely to be many more. Evidence suggests that the phenomenon of residential care has been growing in recent years due to a complex interplay of different factors, among them HIV and AIDS. To date, there is no systematic information on the numbers of children living with or directly affected by HIV who are placed in residential care, the reasons for and the impacts of their placement on individual children, their families and communities and on the residential care facilities themselves. This paucity of data makes it difficult to monitor the success of efforts to support family-based care, prevent separation and promote reunification for all children, including those affected by HIV. It also impairs efforts to ensure that children living with HIV in residential care are able to access HIV-specific services that are supportive and appropriate. In this context, tracking the extent to which the HIV pandemic has been a driver of growth in children's residential care is very difficult.

In recognition of the need to know more about these issues, UNICEF commissioned EveryChild and Maestral International in late 2011 to provide technical assistance and evidence collection in relation to the care of children living with HIV in residential care. Through a combination of desk-based research and in-country data collection, the focus of this exercise is primarily on the extent, quality, impacts and responses to residential care for boys and girls (0-18 years) living with or directly affected by HIV. This report provides information from the desk-based component of this study, which is based on an extensive review of published and grey literature, and information gathered from experts working in this field.

Summary of key findings

The desk-based research revealed limits in both the quantity and quality of existing data available on the links between HIV and residential care. There is a lack of reliable data on this subject, and comparisons are made difficult by the use of varying definitions and data collection methods. Despite these gaps, several conclusions can be drawn from this desk study:

- Despite the attempts of governments worldwide to limit the use of residential care, particularly large-scale dormitory-style facilities, the numbers of such facilities have been increasing over the past several years. Although the extent to which this proliferation is a result of the HIV pandemic is not known. Insufficient attention has been paid to developing options for alternative care, especially, but not exclusively, for HIV-affected children.
- Children living with HIV appear to have restricted and poorer care choices compared to able-bodied, (assumed to be) HIV-negative children. Not only are they more vulnerable to losing their parents at an early age, but high levels of stigma, discrimination and misconceptions about the transmission of the virus mean that in some cases they may be denied kinship care and access to foster care, adoption and some residential facilities. In some contexts, they appear to be institutionalised at higher rates than other children. Insufficient efforts have been made to promote their reintegration within families and communities.
- Children living with HIV have very specific medical needs related to access to treatment, effective monitoring and support. Medical services are essential to their survival and



wellbeing. It is unclear whether residential care facilities are able to provide these types of services to children, and whether boys and girls living with HIV in residential care have fewer opportunities to access HIV services than they would in a family-based setting.

- Children living with and affected by HIV face particular risks to their emotional and social wellbeing. Currently, these needs appear to be inadequately supported in residential care, a finding largely evidenced by the fact that there is so little data on children's HIV status or family HIV-related situation.
- Quality care is compromised in many residential care facilities due to inadequate infrastructure, limited financial resources, lack of appropriate training and supervision of care personnel. There is also limited awareness of child development in general, and the specific needs of children living with HIV in particular. All children need quality care, but children

living with HIV and have direct experience of HIV in the family can often experience negative and long-lasting psychological impacts. HIV infection itself and the poverty caused by HIV in the household can in many cases lead to increased vulnerability to a whole series of risks, including, but not limited to, stunting, illness and delays in a child's cognitive and physical development.

- All children have a right to HIV prevention information and the means to act on this knowledge. The absence of such information in residential care makes doing so impossible. It is well known that children leaving care often risk violent relationships, unwanted pregnancies and other health risks, often because of their formative experiences. Information related to HIV and its impacts, as well as to sexual and reproductive health more generally, is a right for all children in residential care, and is particularly important for children who are themselves HIV positive.

Recommendations for further research

This desk study has identified a series of gaps in knowledge and information that should inform the design of research questions for the four country-level studies soon to be undertaken:

- A more in-depth understanding of the reasons for entry into residential care, and of the links to HIV.
- The quality and quantity of residential care in general, and for children living with and affected by HIV specifically.
- The range of alternative care options available to children living with HIV in both high and low prevalence settings.
- The extent to which HIV is mainstreamed into policies on alternative care, and in regulation and care planning.
- The particular impacts of residential care on children with HIV.
- The extent to which national level health and HIV and AIDS protocols and guidelines are being applied to residential care settings.
- The extent to which all children in residential care – boys and girls – have access to age-appropriate HIV prevention and reproductive and sexual health care.
- The type and kinds of support and interventions in place to strengthen and reinforce the emotional, physical, economic and social care provided by the families and communities of children living with and affected by HIV. This is relevant as it impacts on the root causes of entry into care.
- The identification of successful models of training and support for those working in residential care settings on how to meet the care and protection needs of children affected by HIV, including activities and approaches that strengthen the capacity of families and communities to care for children.
- The perspectives of children affected by HIV and living in residential care.
- The extent to which HIV-affected and HIV-positive children of different ages living in residential care are involved in decisions that affects them.
- The extent and effectiveness of mechanisms for referral and linkages between residential care settings and health clinics.
- Good practice in reintegrating children living with or affected by HIV back into families.

1. INTRODUCTION

In many countries, significant numbers of children are temporarily or permanently cared for in residential care. The exact numbers of boys and girls living in such circumstances is not known, although it is argued to be at least two million globally, and likely to be many more (UNICEF, 2009:19). Evidence suggests that the phenomenon of residential care has been growing in recent years due to a complex interplay of different factors, among them HIV and AIDS (e.g. Dunn and Parry-Williams, 2008; Williamson and Greenberg, 2010). Over the years, many challenges have been overcome in the fight against the disease and its damaging social and economic effects. Paramount among them is a growing focus on the need to ensure that children and adults know their HIV status and have access to antiretroviral therapy (ART); to prevent vertical transmission; and to support children to stay in families and communities (JLICA, 2009). Despite these successes, some children continue to lack access to parental and community-based care (UNICEF 2012). Like all children, boys and girls living with and affected

by HIV are known to thrive better – both physically and emotionally – in supportive family settings, rather than in residential care (UNICEF, 2011).

To date there is no systematic information on the numbers of children living with or directly affected by HIV placed in residential care or the reasons for and the impacts of placement on individual children, their families and communities and on residential care facilities themselves. This paucity of data makes it difficult to monitor the success of efforts to support family-based care and prevent separation and promote reunification, for all children, including those affected by HIV. It also impairs efforts to ensure that children living with HIV in institutions are able to access HIV-specific services that are supportive and appropriate. In this context, tracking the extent to which the HIV pandemic has been a driver of a growth in children's residential care (or a driver of growth in the number of children affected and infected by HIV in residential care) is very difficult.



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In recognition of the need to know more about these issues, in late 2011 UNICEF commissioned EveryChild and Maestral International to provide technical assistance in relation to the care of children living with HIV in residential care. The overall objectives of this work are:

1. To enhance the global evidence base on the placement of children affected by HIV in residential care settings, the reasons for and impacts of this placement, and effective strategies to address this issue.
2. To provide in-depth technical assistance to four countries to improve knowledge and programming and ensure national systems and responses are in line with global recommended practice on HIV and AIDS and alternative care.
3. What are the broader links between HIV and the factors which lead to the residential care of children? What impact has the rising numbers of children 'orphaned' by HIV had on the growth of residential care? What are the likely consequences for children affected by HIV?
4. To what extent are the rights and specific needs of children living with HIV met in residential care? (especially in relation to health care, education, psychosocial support, stigma and discrimination)
5. What are the parallels and differences between HIV and other elements of diversity, including gender and disability issues?

Through a combination of desk-based research and in-country data collection, the focus of this exercise is primarily on the extent, quality, impacts and responses to residential care for boys and girls (0-18 years) living with or directly affected by HIV.

This desk study represents the first step in this process. It includes an analysis of a global survey and a broad review of the available literature on the issue. Its aim is to address the following five sets of questions:

1. What is the extent of residential care for children living with HIV? What are the emerging trends with respect to the residential care of HIV-affected children on the global, regional and national levels?
2. What explanations are there for the rates of children living with HIV in residential care?



2. TERMS AND DEFINITIONS

This report uses the definition of residential care outlined in the *Guidelines for the Alternative Care of Children* welcomed by the UN in 2009 (UN, 2010),

“Care provided in any non-family based group setting, such as places of safety for emergency care, transit centres in emergency situations, and all other forms of short and long term residential care facilities, including group homes” (UN, 2010: Article 29a(iv)).

Within these parameters there are significant variations in the form and quality of care. Arrangements range from large institutions with up to hundreds of boys and girls, to small centres with far fewer children, often run by non governmental organisations (NGOs) or faith-based organisations. Most are guided to some degree by a set of rules and routines. In general, care discontinues once a child reaches the age of 18. The dividing line between residential care and care in hospitals and boarding schools is often extremely thin, especially if children remain in such facilities for long periods of time, with minimal contact with those at home. As noted by Tolfree (1995), care in such facilities may be considered akin to residential care if it replaces, rather than supplements, parental roles and responsibilities.

The concept of residential care includes a wide variety of models across a spectrum. At one end is large-scale **dormitory-style residential care**, in which children sleep in age and sex-segregated dorms and share communal living and dining areas. Staff typically undertake a series of administrative, domestic and care giving roles. At the other end are **small group homes**, in which facilities attempt, more or less successfully, to replicate a nuclear family setting by providing children with the opportunity to develop a consistent relationship with one or more parental figures and a number of ‘siblings’ of differing age and sex. Together, the ‘family’ lives as a

unit and prepares food, eats and undertakes household tasks as they would in an ordinary home. Between these two models lie facilities which combine different aspects of the two approaches, and can include places such as ‘children’s villages’.

Globally, children living with or affected by HIV, like all children, are cared for in facilities which span the range of models, though no reliable data exist regarding the most common model of care.

Other definitions are used throughout this report:

Child: As per the UN Convention on the Rights of the Child, a child is legally recognised as a male or female under the age of 18.

Adoption: A process whereby a child becomes a permanent, legal member of a family other than their birth family.

Alternative care: The care of a child who is not in the overnight care of at least one of their parents (UN, 2010: Article 29a).

Foster care: A planned alternative family care arrangement in which a child is placed by a competent authority in the home of an unrelated family that has been selected, qualified, approved and supervised for providing such care (UN, 2010: Article 29b(ii)).

HIV-affected child: This term refers to a child who has been orphaned by AIDS and/or is HIV positive, as well as those individual boys and girls whose wellbeing or development is threatened by HIV because they live in HIV-affected households and communities (UNICEF, 2011:6).



HIV-positive child/child living with HIV: A child who has had antibodies against HIV detected on a blood or saliva test or at birth through a test to detect the HIV virus itself (UNAIDS, 2011a).

Kinship care: Family-based care within the child's extended family or with close friends of the family known to the child. Kinship care may be formal or informal in nature (UN, 2010: Article 29c(i)).

Orphan: A person under 18 years of age who has lost one or both parents ('single' or 'double' orphans respectively). The term 'maternal orphan' refers to those who have lost their mother, and 'paternal orphan' to those whose father has died (UNICEF, 2011:6).



3. METHODOLOGY

A three-pronged methodology was used to identify all relevant literature and documentation related to the residential care of children living with or affected by HIV.

Global literature search for peer-reviewed articles

Peer-reviewed articles were identified and accessed through a search of key academic search engines such as FirstSearch, ProQuest and Social Science Index. Databases were purposefully searched for articles published in English in approximately the last five years¹ using search terms that included: residential care; alternative care; institutional care; orphanage; parental care; children's homes, alongside HIV; HIV/AIDS; AIDS; child; and orphan.

Web-based search for additional literature, documentation and information

Non-peer-reviewed, or 'grey' literature, was identified and reviewed via a series of databases and search engines. Grey literature included government care plans and National Plans of Action for Vulnerable Children; programme-focused research and situation analyses; programme assessments, evaluations and plans; handbooks, guidelines and frameworks of models of care for children affected by HIV in a series of different contexts. Specific methods for data collection included:

- A search of relevant areas in the Better Care Network database (BCN) including:
 - > Good practice in care arrangements: Assessment and placement monitoring.
 - > Social welfare systems: Child care policies/ country reports and standards of care.

- > Particular threats to children: Children affected by HIV and AIDS.
- > Keyword search by country.

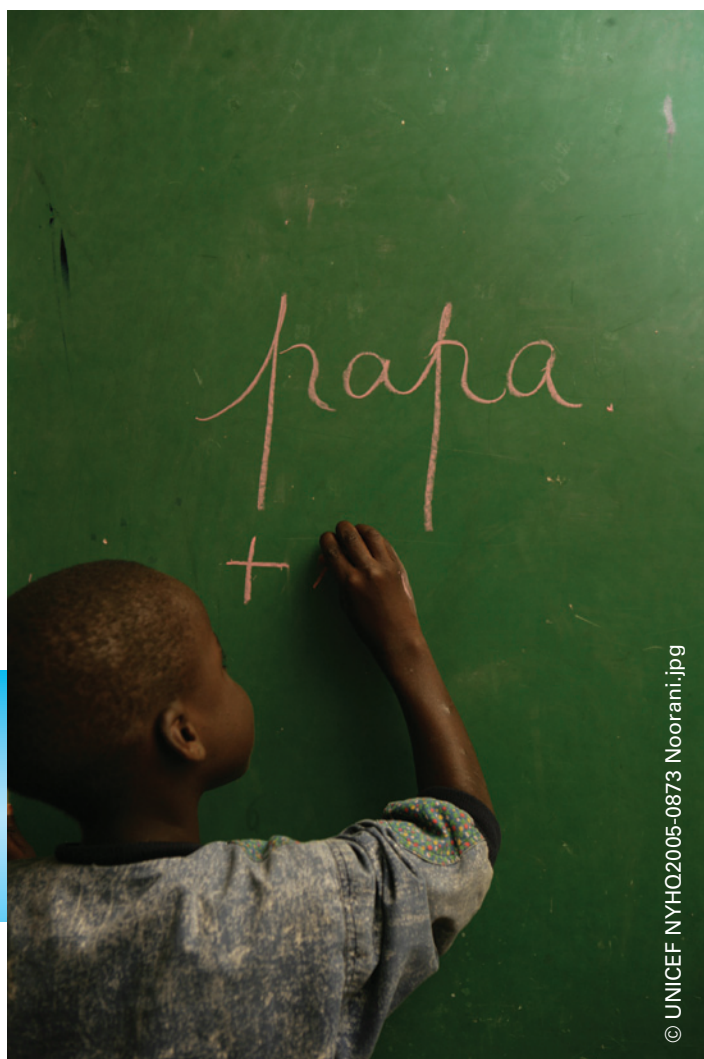
- A search of the Child Rights Information Network (CRIN) database: information by country – national laws.
- A search of OVCSupport.net: Policy and research section – policies + key word search by country.
- A search of Coalition on Children Affected by AIDS (CCABA): Resources – documents and journals on children affected by AIDS.
- A search of JLICA (Joint Learning Initiative on Children and HIV): Resources – publications.
- A search of governments' and ministries' websites (on several occasions relevant documents were identified but often no links were provided or existing links were invalid).
- A search using Google and Google Scholar for terms including: HIV + HIV/AIDS + child + residential care/alternative care/institutional care/orphanage/parental care/children's homes; HIV+ child* + residential care etc; care guidelines; OVC policy; national plan of action; national action plan; care standards; child protection + country.
- A search of the internet to trace documents referenced in successfully sourced documents (i.e. *Pakistan's National Plan of Action for Children* was referenced in *National Guidelines for the Care and Support of Children affected by HIV and AIDS in Pakistan*).

¹ This literature review focused on data from the last five years. However, on occasion when particularly relevant studies were conducted, or more recent data were not found, reference is made to research published before 2007.

- A search of the internet to identify organisations and residential institutions which house and care for children with HIV in countries with the highest prevalence of HIV globally.

Call for evidence

A questionnaire including a request for information about published and unpublished research, relevant national statistics and other questions of relevance was sent to UNICEF country offices, EveryChild country offices and partner organisations, international NGOs and faith-based organisations engaged in child protection and HIV, as well through the Better Care Network Advisory Group, OVCSupport.net and other professional networks and contacts (see Annex 1).



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4. THE CONTEXT OF RESIDENTIAL CARE: A GROWING PHENOMENON

While traditions of care in most parts of the world mean that the vast majority of the 153 million orphaned children worldwide – of whom roughly 17 million have lost one or both parents as a result of HIV – are cared for within extended family networks,² some are not absorbed into community and family structures (UNICEF 2012:103). Some end up in residential care, including in large scale institutions, despite the view widely shared by international agencies, governments, service providers, academics and others, that alternatives to such facilities should be developed, especially for children under three years old (see EveryChild, 2010, 2011; Foster, G, Levine, C, and Williamson, J (eds), 2005; JLICA, 2008; Save the Children, 2003, 2009; Phiri and Tolfree, 2005; UNICEF, 2006a; Williamson and Greenberg, 2010).³ The precise numbers of children in such circumstances is unknown.

There is currently limited data on the linkages between HIV and residential care. It is generally agreed that the HIV pandemic has had devastating social and economic impacts and although the vast majority of orphaned children are cared for within families, the disease has seriously undermined the capacity of families and

communities to support and care for their children.⁴ This is especially the case where HIV prevalence is high, most notably in southern Africa. To illustrate, in 2008 it was reported that of the nearly 17 million single and double orphaned children in the Southern Africa Development Community (SADC), almost 40% had lost their parent(s) because of HIV (SADC, 2008). Despite huge improvements in access to HIV treatment, children affected by and living with HIV continue to be vulnerable to the loss of parental care. Whereas HIV-positive boys and girls were once placed in residential care and were expected to die, with the advent of treatment survival rates have increased dramatically and with them a concurrent increase in the need for care and placement requirements for children.

In some countries, especially those in Eastern Europe and Central Asia, residential care has long been an established solution for many families in distress (UNICEF, 2010a:7). In 2010, it was estimated that 1.3 million children in this region were deprived of parental care, even though the vast majority had biological parents who were living (UNICEF, 2010a). In 11 out of 17 countries studied by UNICEF (2010a), these numbers continue to climb (UNICEF, 2010a:10). For example, in Moldova the number of boys and girls under the age of 18 in residential care increased by 2.75 fold from 2000 to 2007 (UNICEF, 2010b:16). In other regions, including southern Africa and parts of south and southeast Asia, residential care for children is on the increase (UNICEF, 2006a; EveryChild, 2011). Reports from Cambodia, for example, suggest that the number of children in

2 For example, in 2004, Zimbabwe's Ministry of Labour and Social Service reported that less than 2% of orphaned children were not being cared for by relatives. See also Dunn and Parry-Williams, 2008; Mathambo and Gibbs, 2008; Richter et al, 2004.

3 "...Where large-scale residential facilities (institutions) remain, alternatives should be developed" (UN, 2010: Article 23).

"...In accordance with the predominant opinion of experts, alternative care for young children, especially those under three, should be provided in family-based settings. Exceptions to this principle may be warranted in order to prevent separation of siblings and in cases where the placement is of an emergency nature or is for predetermined and very limited duration, with planned family reintegration or other appropriate long-term care solutions as its outcome" (UN, 2010: Article 22).

4 This view is clearly outlined in nearly all policy frameworks and national plans of action for orphaned and vulnerable children reviewed for this study. See also Foster and Williamson, 2000; Hong et al, 2010; MGCCD Malawi, 2011; Morantz and Heymann, 2010; Nyambedha, Wandibba and Aagaard-Hansen, 2003; Phiri and Tolfree, 2005; Roelen and Sabates-Wheeler, 2011; Yates et al, 2010.

residential care rose from 5,700 in 2005 to 8,600 in 2007, with a doubling in the proportion of under-fives in residential care in the same period.⁵ The extent to which these numbers are correlated with HIV prevalence is not known.

Some have argued that the predominant focus on orphans has framed mitigation as an individual rather than a social problem, and that the use of the term 'single' orphan is also misleading (Bray, 2003; JLICA, 2009; Hosegood, 2008). In 2008 it was reported that 88% of children designated as 'orphans' by international agencies actually had a surviving parent, and that approximately 95% of all children directly affected by HIV were continuing to live with their extended family (Hosegood, 2008). Nevertheless, the idea that most orphans and vulnerable children lack family and social networks persists (Meintjies and Giese, 2006). Residential care is growing, in part as a result of successful appeals to support 'AIDS orphans'.⁶ This is particularly though not exclusively (see, for example, Mariam and Seneviratne, 2006) the case in southern Africa, where a study conducted in 2003 by UNICEF in six countries showed a 35% increase in the number of residential child care facilities between 1999 and 2003. In Swaziland alone, research in 2004 found that 80% of the country's children's homes were established in the four years preceding the study (UNICEF, 2006b). In another study in Zimbabwe, it was found that 24 new orphanages were built between 1996 and 2006 (Powell et al, 2004). The responses of governments, international agencies and others to HIV and AIDS are widely viewed as responsible for this proliferation of residential care (for example, JLICA, 2008; Williamson, 2005).

This growth in the number of residential care facilities

for children is happening despite abundant evidence that the large scale, dormitory style facilities used in many settings can cause serious and long-term harm to the children they aim to protect (see Browne et al, 2006; Dobrova-Krol et al, 2010; EveryChild, 2011; Foster, Levine and Williamson, 2005; Johnson et al, 2006; JLICA, 2008, 2009; Richter, 2004; Smyke et al, 2007; Tolfree, 1995, 2003, 2005; UNICEF, 2010a; Webb, 2010). A large body of research, dating back at least 50 years, has convincingly demonstrated the damaging effects of such care on children's cognitive, emotional, social, and behavioural development, particularly for young children.⁷ Many factors, both internal and external to the child, can mitigate or exacerbate these effects. Nevertheless, it is generally agreed that the risks posed to children's wellbeing by removing them from a community and separating them from their parents, siblings, family and friends are significant, as are certain aspects of the residential care environment such as the lack of opportunities to develop the cultural and practical knowledge and skills needed to integrate into the societies in which they live (FHI et al, 2010; UNICEF, 2003 (especially articles 31 and 32), 2006a; Tolfree, 2005). The supportive aspects of family environments – the bond between parent and child, the continuity of care, opportunities for stimulation and participation, personal attention and love – are critical to children's development and wellbeing yet are rarely available even in the most impressive of residential facilities (Allsop, 2011; Browne et al, 2006; Dawes et al, 2007; Drew, Makufa and Foster, 1998; Foster and Williamson, 2000; Harms et al, 2010; Hong et al, 2010; Lee et al, 2007; Smyke et al, 2007; Wolff and Fesseha, 1998). Protecting and caring for children involves

5 Information from the UNICEF/Cambodian Ministry of Social Affairs, Veterans and Youth Rehabilitation alternative care database.

6 An internet search for 'AIDS orphans' produces many appeals from individual institutions.

7 For example Browne et al, 2006; Dawes, Van der Merwe and Brandt, 2007; Dobrova-Krol et al, 2010; Johnson, Browne and Hamilton-Giachritsis, 2006; Smyke et al, 2007; see also Browne 2009 for a history and review of these studies. The powerful evidence provided by these and other studies led to the strict provision against the institutional care of children under the age of three enshrined in Article 22 of the Guidelines for the Alternative Care of Children (cited in footnote 3).

meeting their physical and material needs as well as helping them to feel a sense of belonging and a sense of their place within a web of relationships in a wider world. This fact is increasingly acknowledged, both in a growing body of literature that stresses the pivotal role that families must play in the care and protection of boys and girls affected by HIV,⁸ and in the greater implementation of family-centered approaches (see JLICA, 2008, 2009; Save the Children, 2012).

Despite the overall view that family structures are the best settings in which to support and care for children, some authors decry the tendency to romanticise 'the

family' and overlook the reality that families are not always safe and supportive places (Ansell and Young, 2004; Mann, 2002; Roelen and Sabates-Wheeler, 2011; Williamson and Greenberg, 2010). While many children experience love, care and nurture within family settings, some do not. Abuse, neglect, discrimination, cruelty and unkindness within the family are regular features in some boys' and girls' lives. Others argue that the number of out-of-family orphans may increase dramatically when the present generation of grandparents, responsible in many contexts for a large part of orphan care, has dwindled (Roelen and Sabates-Wheeler, 2011:16; UNICEF, 2010a:2; Zagheni, 2011).

8 See for example, Foster and Williamson, 2000; Foster, Levine and Williamson, 2005; JLICA, 2008, 2009; Roelen and Sabates-Wheeler, 2011; Save the Children, 2003; Tolfree, 1995; Webb, 2010. Comprehensively stated in UNICEF (2011: 19): "Strengthening family-centred approaches to child care can benefit children's cognitive, physical, emotional and mental development".

These understandings apply to all children but, like data on residential care, there are still gaps in our knowledge about the particular risks faced by HIV-affected and HIV-positive children to abuse, violence, exploitation and neglect within the family. Children who have left their birth home to live with extended family



often report discrimination and abuse, especially from stepparents (see for example, Ansell and Young, 2004; EveryChild, 2010; Mann, 2002; Tolfree, 2003). Some live on the streets, migrate elsewhere or seek work in difficult and often exploitative circumstances (see EveryChild, 2010; Save the Children, 2008).

In recognition of these facts a number of authors argue, and many agencies and governments acknowledge, that a range of alternative care options must be developed to support all children who cannot be cared for by their own families, including those living with and affected by HIV. These options may include small group residential care – when rooted in good practice and administered in accordance with international principles – though many argue that this is an option suitable only for a small range of children, such as those requiring specialist support or who do not want to live in a family setting due to factors such as past abuse (e.g. EveryChild, 2011; Dunn and Parry-Williams, 2008; Moses and Meintjes, 2010; Phiri and Tolfree, 2005, UN, 2010). Other options, such as more formal and supported forms of kinship care, domestic adoption and foster care programmes also need to be made available to enable a full range of care choices, from which the more appropriate form of care can be selected for each individual child (see Dawes, Van der Merwe and Brandt, 2007; EveryChild, 2011 FHI et al, 2010; JLICA, 2008, 2009; UNICEF, 2010a; UN, 2010).



5. RESEARCH FINDINGS

The aim of this desk study was to review a broad range of academic, agency and policy literature in order to identify and consolidate available information on the placement of children living with and affected by HIV in residential care. Particular attention was paid to identifying the numbers of affected children placed in residential care, the reasons for their placement, the quality of their care, and the impacts of their placement on individual boys and girls, their families, communities and on the residential care facilities themselves.

Numerous constraints hampered this task. Most of these related to the absence of relevant data or the poor quality of existing data. Establishing the basic facts about residential care for children is no easy task. Straightforward information about the numbers of children's homes, numbers of residents, reasons for admission and the average length of stay are generally unavailable. The data available is riddled with problems of reliability and validity. It is rare for data to be disaggregated by age and sex, models of care to be described, staff-child ratios to be provided or statistics to be consolidated at the national level. Methods for data collection are rarely explained or even reported. These problems are compounded by the fact that many countries only report data from state-run facilities and do not provide information about the numbers or circumstances of children living in residential care facilities privately run by non-governmental or faith-based organisations (the numbers of which are estimated to be large).⁹ The absence of this essential information makes comparisons across contexts both challenging and problematic.

These difficulties pertain to efforts to establish an accurate picture of the general phenomenon of residential care. It is even more difficult to piece together a reliable body of information to ascertain the specific situation regarding the residential care of children affected by HIV. In many countries, basic data on the numbers of children living with HIV are unavailable, for example in the Democratic Republic of Congo,¹⁰ and Lao PDR (Ministry of Labour and Social Welfare, National Committee for the Control of AIDS Bureau and UNICEF, 2004). In those countries where basic information about pediatric infection rates is available – in Malawi (Ministry of Gender, Children and Community Development, 2011), Nigeria¹¹ or Guyana (Ministry of Labour, Human Services and Social Security, no date) – children's HIV status is not routinely tested upon admission to residential care so the numbers of HIV-positive children living in residential care remain speculative and largely unknown. Of the 33 countries whose National Plans of Action (NPAs) care plans and relevant policy frameworks were reviewed for this study (10 of which represent high epidemic contexts) only two provided figures on the numbers of children living with HIV in residential care. It is likely that this lack of data is a reflection of an overall lack of monitoring of residential care and the known problems of tracking the delivery of HIV care and support.

Given these significant challenges, the findings of this research are limited and in many ways speculative. They are one step in the direction of knowing more, and knowing what more to ask.

9 Kathleen Riordan, Better Care Network, personal communication, April 2012.

10 <http://www.avert.org/africa-hiv-aids-statistics.htm>

11 <http://www.avert.org/africa-hiv-aids-statistics.htm>



The scope and scale of residential care and other care options

For children living with HIV

While 3.4 million children under the age of 14 were said to be living with HIV in 2010 (UNICEF, 2012: 103; <http://www.avert.org/worldstats.htm>), as noted above the HIV status of children admitted to residential facilities is often not known.¹² Although very little information is available, there is some evidence, albeit limited, to suggest that HIV-positive children are more likely to be placed in residential care (Guyana survey response; Meintjes et al, 2007; UNICEF, 2006a, 2007). A study of children's homes in four sites in South Africa, Meintjes et al (2007) found that 16% of children under the age of 14 in residential facilities were HIV positive, compared to 1.9% of the general population. HIV prevalence rates among children in residential care have also been found to be higher than average in Russia (UNICEF, 2010a) and Vietnam (International Social Service, 2009). In parts of the Russian Federation, where up to ten percent of women living with HIV abandon

their newborn children, the numbers of children in residential care with HIV are expected to skyrocket. This is partly as a result of a 700% increase in HIV prevalence since 2006 (UNICEF, 2010a:2).

Data on the extent of the residential care of children with HIV were sought from a variety of sources; including academic researchers, international agencies, governments and survey respondents.¹³ As mentioned above, the findings highlighted huge gaps in information and a lack of good quality data on the numbers of boys and girls who live with HIV in residential care.¹⁴ There were no official statistics

12 This absence of information is reflective of the overall lack of data related to the entry of children into care more generally.

13 The survey was sent directly to approximately 30 individuals, many of whom then forwarded it to their colleagues and professional networks, 14 responses were received.

14 In many cases how the data were collected is not reported. The terms used are also not defined: it is not clear, for example, what constitutes an 'institution' (i.e. are both registered and non-registered facilities included? Were children's remand homes included?), nor what age ranges are included in the numbers of 'children' provided (While the term 'children' usually refers to boys and girls under the age of 18, often statistics related to orphanhood and residential care define children as 15 and under. Many studies and reports do not provide definitions of age groups).

or surveys that reported the existence of state-run residential care facilities catering specifically to children living with HIV, although in practice there appear to be several privately run residential care facilities that serve 'AIDS orphans' in particular. In Central and Eastern Europe and the Commonwealth of Independent States, there are also reports of children living with HIV being placed in residential care established specifically for children with disabilities (EveryChild, 2010). The data does not capture any information on hospice care for children (the provision of end of life care for boys and girls, including those dying from AIDS-related conditions), which may in some cases end up as de facto long-term residential care for children living with HIV.¹⁵ This is apparently not the case in Africa, where the children's palliative care movement has a strong focus on family- and community-based care and where there are few facilities providing trained clinical palliative care.¹⁶ It is less clear whether this is the case in Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS), where health services are generally more broadly available.

Similarly, no official statistics or surveys reported the numbers of children living with HIV in residential care. Given the need for many HIV-positive children to take antiretroviral therapy and have close health and nutrition monitoring, it is important to know whether the status of children living with HIV is known at a time that is optimal for the initiation of appropriate clinical care (WHO, 2011a, and 2011b). However, whilst the advent of HIV treatment has made early diagnosis and enrolment in treatment programmes an imperative, these interventions have always been promoted in the context of informed consent and the

assumption of support from family and friends. A key question is whether children in residential care have this protective support. It is also important to know whether those health care providers and professionals who reach out to communities and families with HIV information and education also reach out to residential care facilities.¹⁷ Survey respondents did not report the existence of guidelines on HIV testing for children entering care, either for those who may have acquired the infection sexually or perinatally. In the absence of such guidance, residential care facilities should adhere to national guidelines on infant and child HIV testing where these exist, and follow WHO global guidelines in countries where national guidance does not exist.

Given this lack of data it has not been possible in this desk review to prove irrefutably that there has been an overall rise in children living with HIV in residential care, and in so doing, identify the particular HIV-specific push and pull factors that exist. The inability to do so has implications for our ability to track access to treatment and care for children living with HIV, monitor quality of care in residential care and regulate the link between numbers of children in residential care and HIV in order to maintain national good practice and policy standards. Further country-level analyses may help to clarify these issues in greater detail.

In addition to evidence on the numbers of children living with HIV in residential care, information was also sought on the numbers of children living with HIV in other forms of alternative care, and on the form of residential care that children living with HIV are most likely to be found in. In some settings, such as Ukraine (EveryChild, 2010), South Africa (Moses and Meintjes, 2010:110) and Sudan (Mulheir, no date),

15 The changing face of the HIV epidemic and the growing access to ART is documented in the Haiti case study of the Maison Arc-en-ciel: [http://www.unicef.org/lac/Haiti_Case_Study-Children_made_Vulnerable_by_AIDS\(1\).pdf](http://www.unicef.org/lac/Haiti_Case_Study-Children_made_Vulnerable_by_AIDS(1).pdf)

16 Joan Marston, International Children's Palliative Care Network, personal communication, May 2012.

17 There is some evidence to suggest that this type of outreach exists in some contexts. For example, in South Africa, NGOs such as Big Shoes have projects to promote health care and support to children living in residential care settings. <http://www.bigshoes.org.za/pages/programmes/medical-clinics-and-outreach.php>

there is a widespread belief among social workers that children living with HIV should not or cannot be fostered. Residential care facilities themselves may also perpetuate this view by arguing that children with HIV have specific psychological, academic, spiritual, nutritional and medical needs that are best provided by trained caregivers in a residential setting. Recent research in Ukraine on the experiences of boys and girls living with HIV without parental care found this was the predominant view amongst caregivers in residential care facilities (EveryChild, 2010). This practice not only leads to children being placed in residential care, but also affects the types of facilities they go into. In India, this argument was used as a justification for the segregation of HIV-positive children. In Ukraine and many parts of Eastern Europe, Central Asia and the former Soviet Republics, it has led to developmentally and physically able children with HIV being kept in 'special needs' facilities meant to serve children with physical and intellectual disabilities (EveryChild 2010; UNICEF 2005; UNICEF 2006a: 36).¹⁸ Additionally, in certain residential care settings, caregivers are not always kept up to date on advances in treatment and believe that they are caring for terminally ill children.¹⁹ A cursory search of the internet quickly points to the significant numbers of residential facilities whose existence is founded on these grounds (although there are no quantitative data available to

back up this assertion).²⁰

Paradoxically, research also suggests that in some cases HIV-positive children are denied access to residential facilities because of stigma associated with HIV or fears about the burden of caring or costs of treatment.²¹ This practice has been widely reported, including in India (EveryChild, 2010 and India survey response), and Myanmar (UNICEF, 2006c). Some boys and girls are housed in residential care specifically for HIV-positive children, common in Ukraine (EveryChild, 2010:19), or are separated from the general population within a larger facility, as was reported in the Kenya and Thailand survey responses.²² Decisions about their care are often driven by ignorance about transmission routes and fear of children infecting others. For example, a study of the knowledge, attitudes and practices of social workers in Sudan in 2006 found that 55% thought that HIV-positive children should live in residential care exclusively for children with HIV and 33% believed such children should be isolated from their families and communities in order to avoid infecting others (Mulheir, no date: 30,31). There are also anecdotal reports of greater difficulty in placing healthy but HIV-positive children in family-based or foster care

18 This mistaken practice carries a number of risks. First, children with HIV who do not have physical or intellectual disabilities will be deprived of appropriate care. Second, it may be that such placements are not made on the basis of a proper assessment of the individual child. HIV can delay a child's physical and cognitive growth, as can repeat opportunistic infections, and these need both treatment and rehabilitation. A blanket diagnosis of 'disabled' may prevent these interventions from happening. It is also essential to avoid the risk of stigmatising children with disabilities by implying an association between disability and HIV infection.

19 Amanda Cox, co-ordinator of the Faith to Action Initiative, personal communication, May 2012.

20 For example, see nyumbani.org in Kenya, 'Founded in 1992, Nyumbani Children's Home is an active response to the rising number of HIV infected children born in Africa every day'; choaids.org in Haiti, 'Our mission is to provide a home for HIV+ abandoned children in Haiti through meeting their basic needs to include the building of a non-traditional family'; hope-for-tomorrow.de.in Vietnam, 'In 2001 the orphanage was established to receive HIV-infected children from all over Vietnam'.

21 For example in Myanmar, children with HIV are not permitted to live in the small institutions described as 'family' or 'cottage' care. These facilities are designed to provide a family-like atmosphere in which individualised attention is provided to no more than 10 children at a time by a permanent caregiver who acts as a 'mother' (UNICEF, 2006c).

22 Thailand see Limanonda and Kowantanakul (2009:68); survey response from Kenya.

in the community than HIV-negative children, possibly because of the expectation of high health care-related costs for children who may need to travel to distant health facilities for treatment.²³

For children affected by HIV

As with children living with HIV, the literature indicates that children affected by HIV have fewer care choices than most other children. Such children are more vulnerable to losing parental care (EveryChild 2010; UNICEF 2007).²⁴ Separation from parents can happen as a result of parental death or for extended periods when HIV-positive parents are ill. As with children living with HIV, many of these children are absorbed into the care networks of most families and communities. However, evidence from a number of different contexts suggests that they are also less likely than others to be taken in by kin or to be fostered or adopted in some settings.²⁵ These findings are particularly prevalent in CEE/CIS countries, where children born to HIV-positive mothers have a much higher risk than others of being abandoned at or soon after birth,

“Their removal from their mother, their family and community is an expression of both the stigma surrounding the HIV disease and of the multiple hardships that overwhelm many disadvantaged women” (UNICEF, 2010a:7).

In the Russian Federation and Ukraine it has been reported that about 6-10% of children born to HIV-positive mothers are abandoned in maternity wards,

paediatric hospitals and residential care, with little opportunity for foster care, adoption or family reunification (UNICEF, 2010a:11).²⁶ These findings differ from those from eastern and southern Africa, where the possibility of HIV infection or the HIV status of the mother does not appear to be a common reason for child abandonment. It is not known whether the rejection or abandonment of infants and young children in these circumstances is an issue of concern in countries such as China, India and Thailand. Despite low overall prevalence rates of HIV in these countries, there are high numbers of children born to those who comprise ‘most at risk populations’. Furthermore, the breakdown of these data by age and gender is rarely provided. In fact, obtaining disaggregated information of this kind was a central challenge faced in all aspects of this desk study.

Decisions by families about whether or not to care for children affected by HIV may be driven by stigma, discrimination and ignorance. But, as with all children, poverty is often the key deciding factor, particularly in low income countries (for example, Bray, 2003; Dawes et al, 2007; Williamson and Greenberg, 2010). This simple fact is clearly articulated in a report of the Jamaica National AIDS Committee (2002:6),

“when it comes to caring for orphaned children, community workers are constantly being told the real problem is money: ‘Help us earn a living and we’ll take care of the kids’”

In many contexts the links between poverty, HIV and care options for children are clearly difficult to separate and require careful consideration and investigation.

23 Joan Marston, International Children’s Palliative Care Network, personal communication, May 2012.

24 In Ethiopia for example, 12% of children – more than five million boys and girls – have lost one or both parents, many of them to AIDS (FHI et al, 2010). In 2010, 3% of children in Malawi were identified as ‘double orphans’ (NAC, 2010).

25 In Ukraine, Dobrova-Krol et al (2010:248) report that boys and girls with HIV are the least favoured for adoption or foster care. This is also the case in Guyana (survey response), Malawi (survey response) and Zimbabwe (UNICEF, 2004).

26 It appears that these mothers are from most at risk populations, including intravenous drug users, in which case HIV-related stigma may be compounded by stigma against those who are understood as morally or practically incapable of looking after their children. It is also worth noting that the region is one where institutionalisation has had a long history and may be more rooted in social norms than in other contexts such as east and southern Africa.

The impact of HIV on household wealth levels has been clearly documented and has in large part been the background of the drive toward sustainable safety nets in eastern and southern Africa (Akwara et al, 2010; DFID et al, 2009; Roelen and Sabates-Wheeler, 2011). There is now convincing evidence of the need to provide some form of economic safety net for all vulnerable households, with the acknowledgement that poverty and HIV infection in the family interact in complex ways (Drimie and Casale, 2008; Gillespie, 2008; JLICA, 2008).

In addition to the direct relationship between HIV and factors which contribute to a loss of parental care for individual children (as noted above) there is also evidence that the spread of the disease has been used as a justification for the expansion of residential care facilities in HIV-affected communities. Residential care is growing in numbers, in part as a result of successful appeals to support 'AIDS orphans', partially due to the framing of the impact of HIV on children as primarily related to orphanhood (see above).²⁷ This is particularly, though not exclusively (see Mariam and Seneviratne, 2006), the case in southern Africa. A study conducted in six countries there in 2003 by UNICEF showed a 35% increase in the number of residential care facilities between 1999 and 2003. In Swaziland alone, research in 2004 found that 80% of the country's children's homes were established in the four years preceding the study (UNICEF, 2006b). In another study in Zimbabwe it was found that 24 new orphanages were built between 1996 and 2006 (Powell et al, 2004). The responses of governments, international agencies and others to HIV and AIDS are widely viewed as responsible for this proliferation of residential care (e.g. JLICA, 2008; UNICEF, 2007; Williamson, 2005). It has been widely argued that the very existence of residential care can act as a magnet for parents from impoverished communities seeking a 'better' life for their children (see EveryChild, 2011; Tolfree, 1995). In this indirect manner, responses to the spread of HIV may be seen

as responsible for growing numbers of children being placed in residential care in HIV-affected communities.

In addition to governments, some faith-based groups have responded to reports of growing number of 'AIDS orphans' through the establishment of residential care facilities for children, especially in sub-Saharan Africa (Firelight Foundation, 2008). For example in Zimbabwe, Powell et al (2004) found that over a ten year period, 80% of newly-established residential care facilities were initiated by faith-based organisations. Significant investments in residential care have also been reported in Kenya and Tanzania (EveryChild, 2011:30).

Meeting global standards in children's care

For children living with HIV

Despite the possible increasing prevalence of residential care and that the evidence suggesting children living with HIV may be more likely than other children to be placed in residential care, hardly any comprehensive studies of the effects of residential care on HIV-positive children have been conducted. The few studies that have been carried out in Africa – where more than 80% of children orphaned by AIDS (UN Department of Public Information, 2010) and almost 90% of all HIV-positive children live (Edstrom and Khan, 2009 48) – are small in scale and geared toward the needs of orphaned and vulnerable children in general and not towards HIV-positive children specifically (Johnson, 2011; Morantz and Heymann, 2010; Zimmerman, 2005). One recent study in Ukraine studied both HIV positive and HIV negative institutionalised children under the age of eight. It found that family care, even of a compromised quality, was better for the physical and cognitive development of children than residential care (Dobrova-Krol et al, 2010). HIV-positive boys and girls cared for in disadvantaged families showed better physical and cognitive development not only in comparison to HIV-positive children in residential care but also to HIV-negative, relatively healthy children raised in large scale residential care facilities providing superior

27 An internet search for 'AIDS orphans' produces many appeals from individual institutions.

material and physical environments. Studies like these reinforce existing evidence about the benefits of family-based care. They also point to the need for more research that compares the developmental impact of different care arrangements on boys and girls of different ages in different circumstances over the long and short term. Longitudinal studies that examine these issues have the potential to offer important insights.

Children living with HIV face significant risks to their physical and emotional wellbeing (Cluver and Gardner, 2007b). From the medical perspective, an HIV-exposed infant is vulnerable to communicable disease, malnutrition, developmental delay and early death.²⁸ These children need access to testing and early treatment. Children who are already enrolled on treatment programmes, via PMTCT (Prevention of Mother-to-Child transmission) programmes at and before birth, will need ongoing care and support, including ART when this becomes medically necessary. Asymptomatic HIV-positive children will need consistent medical and nutritional support and HIV monitoring to ensure that they start on early ART when this becomes necessary. Increasingly there are global standards of care for children living with HIV and, at a minimum; children in residential care should be accessing this care. The World Health Organization publishes evidence-based, regularly updated guidelines for the diagnosis and management of HIV infection in infants and children (WHO, 2010a, 2010b). The key recommendations for diagnosis and care are included in Appendix 2. These give a clear picture of the extent of healthcare that children living with HIV require and the critical role of the caregiver, together with the need for adequate information, training and support in order that this role is effectively carried out.

Children living with HIV also have a range of psychosocial support needs, as well as requirements for life skills support as they enter adolescence. Research has

shown that while all children benefit from psychosocial support, it is particularly critical for the health and development of boys and girls living with HIV and those who face multiple stressors related to HIV. These include the illness and death of a parent, disclosure, stigma, discrimination, isolation, loneliness, and family conflict or uncertainty (Kanesathasan et al, 2011).

In addition to these needs which relate specifically to HIV, the alternative care of children living with HIV should also be guided by global standards on alternative care, that apply to all children. These are articulated in the *Guidelines for the Alternative Care of Children* (UN, 2010), which, for example, call for the prioritisation of support to families to care for their own children, and efforts to reintegrate children who have become separated from parents where appropriate and in children's best interest; care planning and review to ensure that children are in the most appropriate forms of care; the importance of child participation in decisions regarding children's care; and supporting children in alternative care to maintain contact with families and communities.

Although research is limited, there is some evidence to suggest that children living with HIV in residential care are not receiving the care and support that such international standards suggest they require:

- **Many facilities have poorly trained personnel,²⁹ lack medical and nutritional supplies, provide little in the way of psychosocial support, have poor infrastructure and provide inadequate facilities.**

29 In South Africa, a NGO called Big Shoes Foundation designed a training course for childcare workers in residential care and community projects in response to the recognised lack of capacity with regard to HIV-related health care. The training covers basic child health and was tailored to address the leading causes of under-five morbidity and mortality. Specifically, the course deals with childhood development; the recognition and management of common childhood illnesses, including HIV and TB; nutrition; hygiene; first aid; and CPR. Between 2006 and 2011, Big Shoes trained more than 2,000 child care workers from over 50 children's homes and over 100 community projects countrywide.

28 http://www.columbia-icap.org/resources/peds/trainingresources/care_hiv_infant.pdf

The absence of data on children living with HIV in residential care would indicate that some, if not many children are unable to access antiretroviral therapy (ART) and other necessary health care.³⁰ Government oversight and monitoring is patchy and often non-existent for unregistered facilities (Williamson and Greenberg, 2010). High child to staff ratios in many residential care settings and an overall lack of supervision suggest that psychosocial and other support is not sufficiently provided (this issue is discussed in more detail below). Lack of caregivers and staff also suggests that it would be difficult to provide the optimum monitoring and care needed to adhere to global standards for paediatric AIDS treatment.

- **Poor levels of HIV awareness among staff leading to limited HIV prevention and treatment support for all children, including children living with HIV.** There is reportedly limited awareness among staff of children's homes of the psychological, behavioural and developmental effects of HIV on children at different ages and developmental stages, as cited in research from South Africa, Zimbabwe, Ethiopia and anecdotally reported elsewhere (Meiring, 2008; Moses and Meintjes, 2010:112; UNICEF, 2004; FHI et al, 2010). Testing protocols and standards or guidance regarding disclosure for children often do not exist in general, let alone in residential care settings (Limanonda and Kowantanakul, 2009; Kanesathesan et al, 2011). The importance of ART and post-exposure prophylaxis are often not understood. Counselling for children is unevenly available and HIV prevention tools such as condoms are sometimes not available, for ideological, practical or financial reasons, within residential care facilities themselves. Of particular

concern are the needs of adolescent boys and girls who need appropriate sexual and reproductive health information and services, support to transition from paediatric HIV care to adult services and ongoing counselling to deal with a chronic and often stigmatising disease (Kanesathesan et al, 2011).

- **Some children have limited access to information and decision-making.** The HIV status of many children living in residential care is unknown. In those cases where children are known to be HIV positive, they are sometimes not told of their status and not consulted or involved in decisions concerning them.³¹
- **There is in general inadequate access to ART.** The number of children receiving ART worldwide increased from 71,500 at the end of 2005 to 456,000 in 2010, though this latter figure represents ART coverage for only 23% of infected children worldwide (WHO, 2011b). Since coverage is generally low, it seems likely that children in residential care may also be missing out on access to ART.
- **Stigma and discrimination against children living with HIV is widespread.** In some settings, the HIV status of children may be used against them by other children and those adults who work in the children's home.³² Some may be refused entry to school (UNICEF, 2010a:42). Others may be subjected to verbal, physical, sexual and psychological abuse, as was reported in Ethiopia and Zimbabwe.³³ In

30 One exception may be in hospice care, although the number of institutional hospice care facilities globally for children is very low and especially so in sub-Saharan Africa, where HIV prevalence is highest (Joan Marston, International Children's Palliative Care Network, personal communication).

31 For example Malaysia (survey response) and Zimbabwe (UNICEF, 2004)

32 In Jamaica, HIV-infected children have been insulted and stigmatised by those who care for them, including clerics, teachers and staff of children's homes (JNAC, 2002:14).

33 For example Ethiopia (FHI et al, 2010); Zimbabwe (UNICEF, 2004: vi).

a recent study among adolescents in an urban area of South Africa (Thupayagale-Tshweneagae and Mokomane, 2012), boys and girls reported feeling stigmatised and discriminated against by peers, caregivers, and teachers, among others. Additionally, placing a child in residential care is sometimes done in response to the stigma and discrimination they experience within families and communities. Caregivers may think that a child will feel better protected and safer to take their drugs in this kind of a care setting. They may also not want to be identified by community members as providing care to HIV positive children or to been seen as HIV positive themselves.

- **Children living with HIV are less likely to have care plans or to have reintegration efforts pursued on their behalf.**³⁴ Programme and policy documents related to reintegration tend to be generic in nature and do not account for the various and unique circumstances that shape children's experience, such as HIV status (Wedge and Kapur, 2011:9). Plans for transitioning boys and girls from residential care to independent or other living arrangements are often inadequate or non-existent. The risks for their future wellbeing include a real risk to health, including possible future negative reproductive health outcomes (Malaysia survey response).

Despite these problems, it is also possible that children living with HIV in residential or other alternative care are actually able to access better health care than children in the wider population. As with access to other basic services, such as education, this may be a driver for children entering residential care in the first place. In resource-poor regions or areas heavily impacted by the AIDS epidemic, families and communities need ongoing and appropriate support to meet the needs of children in their care (e.g. Hong et al, 2011).

For children affected by HIV

There is little doubt that being affected by HIV in many cases augments the risks and challenges that boys and girls face in their lives in general and in residential care in particular. It is nevertheless important to acknowledge that HIV is rarely the only source of vulnerability in children's lives; poverty, hunger, parental illness, lack of access to basic needs and services, overcrowding and poor living conditions as well as factors individual to the child such as gender, cognitive and physical ability, illness, and experience of violence and abuse are also influential in shaping the ways in which children respond and cope with the challenges in their everyday lives. In this respect, HIV-affected children are no different than many other boys and girls.

There are a few studies that examine the psychological wellbeing of children affected by HIV (Cluver and Gardner, 2007b; Cluver et al, 2009; Cluver and Orkin, 2009; Kanesathesan et al, 2011), and the impact not only of their own status and their experience of parental illness and death, but of the often multiple recurrent losses of additional family members, siblings, peers and others. On their own, each of these experiences has potentially negative mental health effects. For example, HIV diagnosis has been shown to increase levels of anxiety and feelings of isolation (Cluver and Gardner, 2007b; Vilsteren et al, 2011). Studies have also found that when children lose a parent to AIDS, they are at greater risk of developing problems such as depression and difficulties in relationships with peers (Cluver, Gardner and Operario, 2009; Demmer and Rothschild, 2011). Risk factors such as these have been shown to interact with one another and to have a cumulative effect on children's health and wellbeing over time (Cluver and Orkin, 2009; Dawes et al, 2007). To date, little is known about how boys and girls of different ages, especially adolescents, cope with these multiple and overlapping experiences in the long and short term (Edström and Khan, 2009; Vilsteren et al, 2011).

34 Survey responses from Myanmar and Cambodia

The psychological wellbeing of children affected by HIV may also be affected by the degree of stigma and discrimination associated with the disease. Residential care is embedded in particular national, local and cultural contexts. In those societies where knowledge and awareness of HIV is limited and contradictory stigma and discrimination are common, both within and outside of residential facilities. These attitudes and practices are fuelled in part by misconceptions about transmission routes and in some cases, associations with immorality and perceptions about the fitness of certain people to parent their children. For example, in Russia this was identified as an issue by survey respondents, who argued that high levels of stigma attached to sex workers, drug users and alcoholics are also applied to their children, who many believe have inherited 'bad genes'. As noted above, some HIV positive women also reported being advised or pressured to abandon their babies by their own families or by health-care professionals. Similar occurrences have been reported in other countries in Eastern Europe and Central Asia (UNICEF 2010a). It is thus the drivers of HIV, and not only the virus itself, that leads to the stigmatisation of boys and girls in these circumstances.

A key question for this study relates to the capacity of residential facilities to meet the psychosocial needs of HIV-affected children. The vast majority of researchers and international agencies argue that institutionalised children do not receive appropriate levels of emotional and practical support for their problems (Drew et al, 1998; Tolfree, 2005; Wolff and Fesseha, 1998). Many boys and girls, childcare professionals and community members agree (e.g. Mann, 2002; Tolfree, 2005). Understandings of the specific ways in which children's needs are and are not being met are becoming more nuanced with the recent increase in the number of small-scale, qualitative studies that have been conducted with children living in residential care.³⁵

For example, research in Botswana by Morantz and Heymann (2010) explores children's reports of missing their families, their sense of disconnection with their communities of origin and their deep ambivalence towards their paid caregivers and other children who live in the care facility. Whilst boys and girls stress the importance of having access to food, shelter and schooling, their comments underscore the fundamental significance of relationships and of feeling a sense of belonging and kinship – real or fictive – to the emotional wellbeing of children.

The importance of caring relationships and children's perceptions of the quality of care they are receiving to their sense of happiness and wellbeing are substantiated elsewhere in the literature on children affected by HIV. The tendency in these works is to stress the critical importance of close and nurturing relationships with consistent caregivers as these have been shown to be a strong predictor of positive coping (e.g. Bray and Brandt, 2007; Cluver and Gardner, 2007a:321; Lee et al 2007). Because care is experienced and performed at the micro, interpersonal level, who cares for children and the kind of relationship they have and develop with a child are the things that matter (Bray and Brandt, 2007). Attention to the relational aspects of children's lives – not just with the adults who care for them, but with siblings, peers and others – provide important insights into children's networks of support and the meaning of 'feeling at home'. How boys and girls establish and maintain these connections is an important area for further research.

Other aspects of residential care have a direct impact on children's psychosocial wellbeing. It is not apparent from the studies and documents reviewed whether or not residential care facilities provide legal support, in terms of entitlements to inheritance, land or other assets, for those children who have lost parents. Furthermore, there is a noticeable gap in the literature on the capacity of residential care facilities to provide support for life skills development and HIV prevention for children living in residential care, despite an

35 In Botswana: Morantz and Heymann, 2011; Kenya: Johnson, 2011; South Africa: Vilsteren et al, 2011.



established link between the psychological and economic impacts of HIV and AIDS and the increased vulnerability of orphaned children to becoming HIV positive (e.g. Cluver., Gardner and Operario, 2009; Traube et al, 2010). Children's feelings of fear, grief and shame, coupled with isolation and a loss of parental love and nurturing underlie this vulnerability (see Bray, 2003; Demmer and Rothschild, 2011; Foster and Williamson, 2000; Mojola, 2011). The strategies boys and girls employ to find love and closeness, to earn money and to distract themselves from the problems that they face can augment their risk of infection. Certain groups of affected children have been found to be especially vulnerable, including girls and children with disabilities: in adolescence and youth, both groups have significantly higher rates of HIV infection than their male and non-disabled peers.³⁶ These risks may be

exacerbated by the reality that many institutionalised children have limited opportunities to establish close and nurturing bonds with a caring adult (e.g. Browne et al, 2006; Dobrova-Krol et al, 2010; EveryChild, 2009; Foster, Levine and Williamson, 2005; Johnson et al, 2006; JLICA, 2008, 2009; Richter, 2004; Smyke et al, 2007; Tolfree, 1995, 2003, 2005; UNICEF, 2010a; Webb, 2010).

Of course, as with children living with HIV, it is also the case that general global standards on alternative care for children should be applied to children affected by HIV. The general evidence on residential care suggests that all too often these standards are not adhered to, particularly for the care of children in large-scale facilities (EveryChild, 2011; Williamson and Greenberg, 2010).

36 Girls' and young women's disproportionate vulnerability is most striking in southern Africa where females aged 15–24 years are up to as much as eight times more likely than their male peers to be HIV positive. Moreover, among sexually active youth, 23% of orphans reported having had sex by 13 or younger, compared to 15% of non-orphans (Thurman et al 2006). Studies in Zimbabwe have shown that adolescent orphaned girls are significantly more likely to become infected with HIV than their non-orphaned (or male) peers (Birdthistle et al, 2008; Gregson et al, 2005). The gendered dimension of HIV vulnerability was mentioned in several NPAs reviewed for this study, and the 'double burden' that HIV-related difficulties places on children with disabilities was specifically acknowledged by the governments of Nigeria and Zimbabwe in their policy papers. [Federal Ministry of Women Affairs and Social Development](#) (Nigeria) 2004; Ministry of Labour and Social Service (Zimbabwe) 2004.



6. CONCLUSIONS

Summary of key findings

Although there is a strong research base on issues related to the impact of residential care on child development, there remain significant gaps in our understanding of the experiences and impacts of residential care on children living with or affected by HIV. First, there is an overall absence of good quality data on the phenomenon of residential care in general. The little information that is available is riddled with problems of reliability and validity. Second, limitations in the statistics and reporting on children and HIV, inconsistencies in reporting definitions of residential care and the absence of age and gender disaggregated data have impaired our ability to understand how specific individuals and groups of children are affected. The result is that much of what we know is patchy, piecemeal and speculative. Third, there is a lack of long-term studies that examine the outcomes for children of different approaches in different geographical settings, including limited participatory research with children living with or affected by HIV. Fourth, there is little detailed analysis regarding the impacts of different options for the alternative care of children in general, and those with HIV specifically.

Despite these shortcomings in the quality and type of data available, several conclusions can be drawn from this desk study:

- Despite the emphasis of governments worldwide to limit the use of residential care, particularly the use of large-scale, residential care, the numbers of such facilities have been increasing over the past several years, although the extent to which this proliferation is a result of the HIV pandemic is not known. Insufficient attention has been paid to developing options for alternative care, especially, but not exclusively, for HIV-affected children.
- Children living with HIV appear to have restricted and poorer care choices compared to able-bodied, HIV-negative children. Not only are they more vulnerable to losing their parents at an early age, but high levels of stigma, discrimination and misconceptions about the transmission of the virus mean that in some cases they may be denied kinship care and access to foster care, adoption and some residential facilities. In some contexts, they appear to be institutionalized at higher rates than other children. Insufficient efforts have been made to promote their reintegration within their families and communities.
- Children living with HIV have very specific medical needs related to access to treatment, effective monitoring and support. These medical services are essential to their survival and wellbeing. It is unclear whether residential care facilities are able to provide these types of services to these children, and whether boys and girls living with HIV in residential care have less opportunity to access HIV services than they would were they to live in a family-based setting.
- Children living with and affected by HIV face particular risks to their emotional and social wellbeing. Currently, these needs appear to be inadequately supported in residential care, a finding largely evidenced by the fact that there is so little data on children's HIV status or family HIV-related situation.
- Quality care is compromised in many residential care facilities due to inadequate infrastructure, limited financial resources, lack of appropriate training and supervision of care personnel, and limited awareness of child

development in general, and the specific needs of children living with HIV in particular. All children need quality care, but children who are living with HIV and have direct experience of HIV in the family can often experience negative and long-lasting psychological impacts. HIV infection itself, and the poverty caused by HIV in the household, can, in many cases, lead to increased vulnerability to a whole series of risks including, but not limited to, stunting, illness and delays in a child's cognitive and physical development.

- All children have a right to HIV prevention information and the means to act on this knowledge. The absence of such information in residential care makes doing so impossible. It is well known that children leaving care often risk violent relationships, unwanted pregnancies and other health risks, often because of their formative experiences.³⁷ In the context of HIV, information related to the virus and its impacts, as well as to sexual and reproductive health more generally, is a right for all children in residential care, and is particularly important for children who are themselves HIV positive.

Recommendations for further research

This desk study represents the first of two phases in a larger research project. It has identified a series of gaps in knowledge and information that should be incorporated into the design of research questions for the four country-level studies soon to be undertaken. These can be grouped into two general categories:

Generating evidence to inform policy and responses

- **A more in-depth understanding of the reasons for entry into residential care, and of the links**

to HIV. Examining the linkages between HIV and the complex array of factors that lead to children being placed in residential care including, but not limited to, poverty, lack of access to basic services, and violence and abuse in the home.

- **The need to improve the quality and quantity of data available on residential care in general, and for children living with and affected by HIV specifically.**
- **The need for a more in-depth understanding of the range of alternative care options that are available to children living with HIV in both high and low prevalence settings.** In what ways do family, social workers and others promote or discourage family-based care options such as foster care and adoption?
- **An improved understanding of whether and the extent to which HIV is mainstreamed into policies on alternative care.** Are policies and interventions for children living with and affected by HIV led by those in the HIV sector informed by international and national standards on alternative care, such the *Guidelines for the Alternative Care of Children*?
- **An improved understanding of the particular impacts of residential care on children with HIV** (i.e. psychosocial, cognitive, motor, behavioural, etc). It would also be important to explore any parallels and differences between HIV and other elements of diversity, including gender and disability issues.
- **Further information on regulation and care planning.** Are residential care facilities regularly inspected and monitored, including with respect to the decisions that are made regarding the placement and reintegration of children living

37 See for example, Tolfree, 1995.

with and affected by HIV? What is the level of understanding among social service providers of these needs and the risks and benefits associated with different forms of care?

- **The extent to which national level health and HIV and AIDS protocols and guidelines are being applied to residential care settings.** What are the barriers to their implementation? Are staff in residential facilities trained on HIV prevention, care, drug protocols, PMTCT and Post Exposure Prophylaxis (PEP) and universal precautions? Is there regulatory oversight of residential care that provides medical care for children living with HIV?
- **The extent to which all children in residential care have access to age-appropriate HIV prevention and reproductive and sexual health care.** Is this provided in a way that is sensitive to the particular information and psychosocial support needs of children who have HIV themselves, or who may have experienced illness and stigma due to HIV at a young age?

Identifying good models of care and support for HIV-positive children at risk of or in residential care

- **The need for better information on the type and kinds of support and interventions in place to strengthen and reinforce the emotional, physical, economic and social care that is provided by families and communities to children living with and affected by HIV** (i.e. to address stigma and discrimination, the emotional burden of living with the disease and caring for sick family members, poor access to health care, poor access to social protection schemes and bouts of illness that make it difficult for many families to earn a livelihood). This information would also provide important

additional insights into the root causes of entry into care.

- **The identification of successful models for training and support** for those working in residential care settings on how to meet the care and protection needs of children affected by HIV, including activities and approaches that strengthen the capacity of families and communities to care for children.
- **The perspectives of children living in residential care** about their experiences (psychosocial, emotional, material, educational, etc) as boys and girls affected by HIV and living without parental care. It would also be important to look at the differences in the experiences of maternal, paternal and 'double' orphans and to examine whether these different types of orphanhood lead a child to be more or less likely to be placed in residential care.
- **The extent to which HIV-affected and HIV-positive children of different ages living in residential care are involved in decisions that affect them** (i.e. about medical care, disclosure, placement preferences, family reunification and reintegration, etc).
- **The extent and effectiveness of mechanisms for referral and linkages** between residential care settings and health clinics. Are such linkages commonly made, to what extent children are followed up on, and what services do they receive?
- **Good practice in reintegrating children living with or affected by HIV back into families.**



ANNEX 1: SURVEY

Global survey: the links between HIV and the residential care of children

Introduction

UNICEF has commissioned EveryChild and Maestral International to provide technical assistance in generating an evidence base on the links between HIV and residential care. Through a combination of desk-based research, and in-country data collection, this work will aim to provide evidence on:

- The extent of the institutionalization of children living with and affected by HIV;
- Particular challenges in residential care facilities for children living with HIV, in relation to access to appropriate health care and nutritional support, stigma and discrimination, and isolation from families and wider communities as a result of responses to HIV status;
- Effective strategies to prevent a loss of parental care for children living with HIV and support their reintegration back into families or communities if they have been separated,
- Access to forms of care other than residential care for children living with or affected by HIV (such as foster care or adoption)

A brief review of the literature suggests that information on these topics is sparse. This survey is designed to augment our evidence base through the solicitation of both published and unpublished reports, and anecdotal information. These data will help us to identify areas for further, in-depth, country-level research on this topic in the second phase of this study.

Please note that we define residential care following the Guidelines for the Alternative Care of Children as: “Care provided in any non-family based group setting, such as places of safety for emergency care, transit centres in emergency situations, and all other forms of short and long term residential care facilities, including group homes.” (UN 2009)

Please return this survey to: policy@everychild.org.uk, by the 31st of January 2012. We would prefer written responses to this survey, but if you would prefer to arrange a telephone interview on this topic, please contact us at this email address.

BACKGROUND INFORMATION

Your name: _____

The name of your organisation: _____

The country/ countries in which you work: _____

Your email address: _____

QUESTIONS

1. Are there any figures on the numbers of *all children* living in institutional care in your country/the countries in which you work?

- ☐ Yes
☐ No
☐ Don't know

If yes, please provide us with the figures on the number of children in institutional care and the source of this information.

2. Are there any figures on the numbers of *children living with HIV* in institutional care in your country/ the countries in which you work?

- ☐ Yes
☐ No
☐ Don't know

If yes, what are the figures and source?

3. Is the HIV status of children in residential care routinely tested?

- ☐ Yes
☐ No
☐ Don't know

4. Is the HIV status of children in residential care recorded?

- ☐ Yes
☐ No
☐ Don't know

Please indicate any policies relating to HIV testing of children without parental care that you are aware of:

5. From your experience in the country/ countries in which you work, do you feel that the institutionalisation of children living with HIV, as compared to children in the general population is:

- ☐ More common
- ☐ Less common
- ☐ The same
- ☐ Don't know

Why do you think this is the case?

6. Are there any institutions/ residential care facilities in your country/ the countries in which you work which have been specifically established for children living with HIV?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please provide details if you have them (for example, a rough estimate on how many such facilities there are; are these facilities specialist medical care or hospice facilities?)

7. Are children living with HIV in residential care usually:

- ☐ Segregated from other children
- ☐ Mixed with other children
- ☐ It varies
- ☐ Don't know

8. Is there any evidence to suggest that the HIV epidemic had any impact on the overall numbers of children in residential care in your country/ the countries in which you work?

- ☐ Yes, it has led to more children overall who are outside of parental care
- ☐ Yes, it has been used as justification for increasing the number of such facilities
- ☐ No, it has had no impact
- ☐ Don't know

Please explain provide further details and sources of information on this.

9. What are the main challenges faced by children living with HIV in residential care in your country/ the countries in which you work? Please describe in as much detail as you can.

10. If you have a state run foster care programme in your country/ the countries in which you work, is the foster care of children living with HIV, as compared to children in the general child population:

- ☐ More common
- ☐ Less common
- ☐ The same
- ☐ Don't know

Why do you think this is the case?

11. If you have a domestic adoption or kafalah programme in your country/ the countries in which you work, is the adoption/ kafalah of children living with HIV, as compared to children in the general population:

- ☐ More common
- ☐ Less common
- ☐ The same
- ☐ Don't know

Why do you think this is the case?

12. If you have inter-country adoption in your country/ the countries in which you work, is the inter-country adoption of children living with HIV, as compared to children in the general population:

- ☐ More common
- ☐ Less common
- ☐ The same
- ☐ Don't know

Why do you think this is the case?

13. In your country/ the countries in which you work, is the extended family care of children living with HIV, as compared to children in the general population:

- ☐ More common
- ☐ Less common
- ☐ The same
- ☐ Don't know

Why do you think this is the case?

14. In your country/ the countries in which you work, does the National Plan of Action on HIV and AIDS and/ or children affected by HIV and AIDS discuss residential care or other forms of alternative care?
- ☐ Yes
 - ☐ No
 - ☐ Don't know
 - ☐ We don't have such an NPA
15. In your country/ the countries in which you work, does the national level guidance on children's alternative care (e.g. guidance on the use of residential care; guidance on foster care; relevant sections of children's acts, legislation specifically on care) include any reference to HIV and AIDS?
- ☐ Yes
 - ☐ No
 - ☐ Don't know
 - ☐ We don't have such guidance

If yes, please provide us with the title of the relevant guidance or legislation on alternative care.

16. What documentation is there in your country/ the countries in which you work that may be relevant to this research? (think about the questions listed above, along with the four bullet points in the introduction). Can you suggest anything we should read, including:
- ☐ Unpublished reports, such as project evaluations
 - ☐ Government statistical analysis
 - ☐ Published research reports
 - ☐ Relevant policies or guidance

Please attach copies of any relevant reports, or provide us with titles and authors so that we can search for them.

17. Any other information you think might be relevant for us?

Thank you for your time



ANNEX 2: WHO GENERAL STANDARDS FOR THE CARE OF CHILDREN LIVING WITH HIV

HIV testing

As noted above, careful consideration will need to be given to decisions about routine testing of children for HIV in residential care facilities. If testing is conducted, it must be age appropriate. In general, HIV exposure should be established as soon as possible after birth. Infants (babies under 12 months of age) with evidence of HIV-exposure should have a virological HIV testing at 4–6 weeks of age, or at the earliest opportunity thereafter, to diagnose HIV infection. For infants and babies under 18 months of age for whom the HIV-exposure history is unknown, an HIV serological assay should be used to screen for HIV exposure. If this test is reactive, HIV infection is diagnosed using virological testing. For children older than 18 months, an HIV serological assay should be used to diagnose HIV infection.

Baseline assessments of infants and children infected with HIV

The recommended baseline clinical evaluation of HIV-infected infants and children includes growth measurement, assessment of nutritional status, clinical staging of HIV disease, screening for malaria, TB disease and exposure to TB and other concomitant medical conditions, screening for concomitant medications and assessing the child and caregiver's preparedness for therapy. The recommended baseline laboratory assessments include confirmation of HIV infection using a serological or virological HIV test as age appropriate, %CD4 or absolute CD4 count as age appropriate, viral load, haemoglobin, white cell count, hepatitis B and C and a pregnancy test in sexually active adolescent girls. Some of these tests may not be available in certain settings, especially viral load, white cell count and hepatitis assays. However, this should never delay or prevent the initiation of ART.

Antiretroviral treatment

The most recent WHO guidelines recommend that infants and children under 2 years of age should start ART immediately upon diagnosis. Eligibility for older children is determined using CD4 assays.

Routine monitoring of children not yet eligible for ART

Because HIV disease progresses more rapidly in infants and children than in adults, frequent clinical evaluation and laboratory monitoring is essential. Clinical evaluation in HIV infected children who are not yet eligible for ART should include the same parameters as those mentioned for the baseline assessment above and should occur at a minimum of every 3 to 6 months. CD4 monitoring should be performed every 6 months to determine eligibility for co-trimoxazole prophylaxis and/or ART. WHO recommends that all infants exposed to HIV should be started on Cotrimoxazole Preventative Therapy in the first 4–6 weeks of life.

Routine monitoring of children on ART

The frequency of clinical monitoring of infants and children on ART depends on their response to ART. Frequent evaluation is required in the first 3 months after initiation of ART for all children, and infants need more frequent follow up in their first year of life than do older children. The minimum recommended schedule for follow up visits is:

- For infants: At weeks 2, 4, 8, 12 and then every 4 weeks for the first year;
- For children: At weeks 2, 4, 8, 12 and then every 3 months until the child is stable on ART.

Routine clinical evaluation of infants and children on ART should include growth monitoring, developmental assessment, nutritional assessment, screening

for concomitant disease and seeking evidence for the child's clinical response to ART (e.g. improved symptoms, improved growth, improved WHO stage and decreased frequency of infections) and screening for symptoms and signs of drug toxicity and/or treatment failure. The child and caregiver's understanding of and adherence to treatment should be assessed as well as their need for additional support with regard to education, adherence and disclosure.

CD4 monitoring is recommended at a minimum of 6 months after initiation of ART and every 6 months after that. Routine monitoring of viral load is considered desirable but is not essential where capacity and resources are limited. Other routine tests to monitor toxicity are advised according to the use of specific ARVs.

TB

Any child with active TB disease should begin TB treatment immediately, and start ART as soon as tolerated in the first 8 weeks of TB therapy, irrespective of CD4 count and clinical stage. Isoniazid preventive therapy (IPT) for 6 months is recommended for all HIV-infected infants and children who are exposed to TB but do not have evidence of active disease. Children older than one year without a history of exposure and in whom active TB disease is unlikely should receive IPT as part of a comprehensive package of HIV care.

Nutrition

The nutritional status of HIV-infected children, including height and weight measurements and assessment of diet quality and quantity, should be assessed routinely at all scheduled visits, particularly after the initiation of ART. Children who have weight loss, evidence of poor growth, conditions that require increased energy or are malnourished should receive additional energy in their daily diet.

Adolescents living with HIV

WHO defines adolescence as the period between 12 and 19 years of age and points out that the physical, psychological and sexual changes associated with

this period have implications for the provision of appropriate HIV treatment and care to HIV-infected adolescents. Adolescents who were infected perinatally often face considerable physical challenges including stunting, late puberty and, in girls, delayed and/or irregular menstrual cycles. In addition to the potential effects on an adolescent's self-esteem, these challenges may complicate a health worker's decision about whether to follow ART guidelines for adults or children. Thus, WHO recommends that the choice of ART regimen and dosages for adolescents be based on assessment and rating of sexual maturity. Adherence to long-term therapy and retention in care is also recognized as a particular challenge in adolescence (Dodds et al 2003). As adolescents mature sexually, they need sexual and reproductive health education, access to youth friendly health services and contraceptive advice and methods.



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