DIVISION OF POLICY AND PLANNING

COLLECTING DATA FOR NATIONAL INDICATORS ON CHILDREN ORPHANED AND MADE VULNERABLE BY AIDS: A METHODOLOGICAL REPORT

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Contents

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Executive Summary

The numbers of children orphaned and made vulnerable by HIV/AIDS is increasing as the epidemic ages. This number is not likely to decrease for at least 10 years after the epidemic has peaked. A major challenge to governments, international agencies and NGOs is the need to monitor the well being of children who are left behind or affected by this epidemic. Indicators and tools to monitor the national responses toward the commitments made by governments in the Declaration of Commitment on HIV/AIDS in the areas of care and support for children orphaned and made vulnerable by AIDS are needed.

A set of monitoring indicators were developed in the *Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS* (UNICEF and others 2005), however, many of the indicators in the guide had not been field-tested. In addition, there was concern that household surveys, the recommended tool for collecting these national-level data, would not capture the true picture of all orphaned and vulnerable children living in a community, because they did not collect data from children who were living outside of households, such as those living in institutions or on the street. Those children outside of households are missed by household surveys; yet they are more likely to have the lowest education levels, variable health, and overall poorest outcomes than other children.

Two pilot surveys in Blantyre, Malawi and Kingston, Jamaica tested the proposed indicators and methodology. The pilot surveys examined how to best define the children who are made vulnerable by AIDS for measurement purposes. In addition, an integrated sampling technique was developed to test a methodology for merging data collected from children residing in households, in institutions, and children that are homeless. Finally, the pilot surveys re-evaluated the definition used in an indicator for measuring care and support for chronically ill household members.

1. National-level indicators on children orphaned and made vulnerable by HIV and AIDS (OVC) can be obtained through household-only surveys. It is not necessary to collect and merge data on institution and street children to get national indicators.
National household surveys can be used to collect representative and accurate data on all children including children orphaned and made vulnerable by HIV and AIDS. Significant resources will be saved because the complicated data collection and merging steps will not need to be implemented to calculate national indicators.

2. OVC indicators are feasible to measure with sufficiently large sample size.
A number of the indicators were adequate for inclusion in major survey instruments. A few were found to need additional work and re-testing. The pilot surveys provided monitoring and evaluation experts a better understanding of what questions can be posed to children to monitor their well-being.

3. Vulnerable children were found to be worse off than orphans; it is therefore critical to look at indicators by vulnerability status, independent of orphanhood status.
Children who were reported to live in households where an adult was sick or had recently died were in worse conditions than orphans. This is probably because many of the orphans might have

lost their parents 5, 10 or even 15 years earlier and the detrimental effects of that death are no longer evident in our measures; households where an adult is sick represents a current situation, whereas orphanhood is a past situation.

4. Data from household surveys on children orphaned and made vulnerable by HIV and AIDS should only be collected in countries with a high prevalence of HIV (over 5 per cent) OR a high level of orphanhood (over approximately 8 per cent of children age 0–17 having lost one or both parents). Data on care and support for chronically ill persons should only be collected in countries with a high prevalence of HIV (over approximately 5 per cent).

1. Introduction

The number of children orphaned and made vulnerable by AIDS is increasing rapidly in sub-Saharan Africa. In 1990, there were an estimated 1 million children who had lost one or both parents due to AIDS in sub-Saharan Africa; in 2005 this estimate had increased to 12.2 million children orphaned by AIDS (UNAIDS 2006). This number does not reflect the number of children who are vulnerable because their parents are chronically ill or their livelihoods are in jeopardy because other adults around them are chronically ill and need care.

As these numbers increase, a major challenge to governments, international agencies and NGOs is the ability to monitor the well being of these children. UNICEF convened an effort to develop indicators and tools to monitor national responses toward the commitments made by governments in the UN General Assembly Special Session on HIV/AIDS Declaration of Commitment in the areas of care and support for children orphaned and made vulnerable by AIDS.

In April 2003 a global consultation of programme and monitoring experts was held in Gaborone, Botswana to discuss monitoring efforts around children orphaned and made vulnerable by AIDS. A list of potential indicators was initially compiled for monitoring at national level. However, many of these indicators were newly defined and had not been field-tested.

In addition, there was concern that household surveys, the recommended tool for collecting these national-level data, would not capture the true picture of all orphaned and vulnerable children living in a community, because they did not collect data from children who were living outside of households, such as those living in institutions or on the street, and were therefore especially vulnerable.

In standard household surveys it is not appropriate to ask respondents about their HIV status or the HIV status of other members of the household. Thus to get a true measure of whether a child is orphaned or vulnerable by AIDS is not possible. Instead instruments must be designed that collect information that can be used as a proxy definition for a household affected by AIDS. Although the indicators aim to collect data on children affected by AIDS they actually measure the situation of wider selection of children vulnerable due to many causes.

During the Gaborone consultation a proxy definition of children orphaned and made vulnerable by AIDS for monitoring purposes was discussed but was not decided upon. An *orphan* had previously been defined as a child who had lost one or both parents, but agreeing on a definition for *vulnerable* was more complex.

There are currently different definitions for children orphaned and made vulnerable by HIV and AIDS (OVC) being used for different purposes; definitions used for programmatic purposes are unique to individual programmes and thus are poorly suited to use for monitoring and evaluation (M&E) purposes. Similarly the definitions used for M&E purposes are designed to collect a consistent sample over time and might not be a complete sampling of all children who are vulnerable. Thus another objective of the pilot survey was to look at the different definitions of OVC and to propose a standard definition appropriate for monitoring purposes.

This report summarizes the findings from two pilot surveys that were carried out to test an integrated sampling technique and to examine new indicators on monitoring the response to children orphaned and made vulnerable by AIDS and young people in general. The OVC Pilot Survey was conducted in 2004 in Blantyre, Malawi and Kingston, Jamaica. This survey was designed to: (1) test the methodology and sampling techniques that were under development for collecting data from separate sub-populations of children residing in institutions and those that are homeless; (2) consider the feasibility of merging the data collected in multiple settings (i.e. households, institutions, and the street) to provide a single estimate of OVC prevalence and unbiased estimates of OVC characteristics; (3) test possible definitions for monitoring the well-being of children orphaned and made vulnerable by AIDS; and (4) to evaluate the reliability and efficacy of proposed new OVC care and support indicators. The final proposed indicators are described in the *Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS* (UNICEF and others 2005).

The two surveys were funded primarily by UNICEF and the US President's Emergency Plan for AIDS Relief through USAID. Supplemental funding for the surveys was provided by the UNAIDS secretariat and the US Fund for UNICEF.

2. Methodology and Implementation

The two settings of Blantyre, Malawi and Kingston, Jamaica were chosen in part to differentiate between OVC living in a high HIV-prevalence setting (Blantyre, estimated adult HIV prevalence of 20 per cent) and those living in a low HIV-prevalence setting (Kingston, estimated HIV prevalence of 2 per cent). In addition the two sites were believed to have different levels of children living on the street. Kingston was perceived to have large numbers of street children, while Blantyre was considered to have a fairly typical population of street children for Eastern and Southern African cities. In addition, strong local counterparts existed in both cities.

Sampling methods were devised for selecting both institutionalized and homeless children and these methods were tested for feasibility in the Blantyre and Kingston surveys.[1] The pilot test questionnaires were administered to a sample of homeless children, children in institutions and children in households to test indicators and to provide overall estimates of OVC and their characteristics.

The fieldwork in the city of Blantyre took place from April 5 through May 14, 2004. The Malawi National Statistics Office (NSO) implemented the survey under the technical guidance of the Demographic and Health Survey Program (DHS) of ORC Macro International (ORC Macro) and UNICEF-Malawi. Additional technical and logistical support was provided by UNICEF-New York. The NSO collaborated with national and international organizations working in the field of child and youth protection, in particular, the Blantyre Social Welfare Office (Ministry of Gender, Youth and Community Services). Two NGOs that assist street children in Blantyre – The Samaritan Trust and the Chisomo Children's Club – were selected to implement the street portion of the survey, due to their extensive knowledge of the street children issues and contacts with the street children of Blantyre.

The fieldwork in Kingston took place from July 5 through August 13, 2004. The Statistical Institute of Jamaica (STATIN) implemented the household and institution components of the Jamaica survey under the technical guidance of the Demographic and Health Survey Program of ORC Macro and UNICEF-Jamaica. Children First, an NGO that assists street children in Spanish Town and the Kingston Metropolitan Area, implemented the street component of the survey. Children First has a strong history of working with children living and working on the street.

[1] A complete explanation of the sampling methodology can be found in 'Guidelines for Sampling Orphans and Other Vulnerable Children' by Anthony G. Turner at www.childinfo.org.

3. Sampling

Perhaps the most difficult challenge for sampling institutionalized and/or homeless children is the development of accurate, complete and current sampling frames. Once the frames have been compiled, sampling from them is a relatively straightforward process that presents no special problems. Sample implementation for homeless children does, however, present issues and problems, as discussed below. In both countries, the three sampling frames – household, institution, and street – were drawn using identical geographic boundaries to ensure comparability of the samples.

Households
The 1998 Malawi Census was used as the sampling frame for the Blantyre survey. The sampling frame was updated for the 2000 Demographic and Health Survey. In the sampling frame, Blantyre city includes 411 enumeration areas, twenty of which were selected for the survey. Each area constituted one cluster in which a complete list of households was prepared. From these lists, 20 households were selected in each cluster to be interviewed.

The 2001 Jamaica Census was used as the sampling frame for the Kingston survey. Twenty-five enumeration areas were chosen from the Kingston Metropolitan Area out of a total of 1,500 enumeration areas. Each of these primary sampling units constituted a cluster. A complete list of households living in each cluster was prepared. From these lists, 32 households were selected in each cluster to be interviewed. More households per cluster were selected in Kingston to increase the sample size among young people in households.

Institutions
The development of a sampling frame for the institution portion of the survey was simple in concept and consisted merely of compiling a complete list of all group-living facilities in Blantyre and Kingston where children might reside. This list of facilities included orphanages, short-term foster care centres, juvenile detention centres, adult jails that might house children under 18 years old, religious group quarters, military barracks, worker's dormitories and other facilities where children might reside. To compile this list, systematic interviews were conducted with public health, social services and law enforcement officials serving those cities, inquiring about the names and locations of any group-living facility housing children under 18. The instrument for this process was a form that was administered systematically to appropriate government officials, religious organizations and NGOs that provided services to children. The institutional sampling frame should be fairly accurate, complete and up to date, however, institutions where illegal activities are taking place – such as brothels or sweatshops – may be difficult or impossible to include in a sampling frame.

The final lists of institutions that comprised the frames reveal that, in both cities, there are comparatively few institutions where children reside – 12 in Blantyre and 31 in Kingston. Because there were so few institutions, all of them were included in the pilot survey samples. Thus there was no need to stratify the institutions on the basis of size and to sample accordingly. The number of residents in these institutions was also unexpectedly small – only 568 in Blantyre and 1,231 in Kingston. As mentioned, sampling the residents was fairly straightforward. This was done by compiling rosters of all children in each of the institutions, from which a systematic

sample of 1 in 2 children in each institution was selected in both cities. (The sampling fraction was large because of the need to have sufficient sample sizes for the institutional component of the pilot survey.) Thus, 284 children were selected in Blantyre and 616 were selected in Kingston.

Homeless children

Unlike the institutional sector, developing a sample frame for homeless children was not simple. It is important to first explain the definition of homeless children from the point of view of this exercise. Street children can be sub-divided into two categories: 'homeless children' and street-working children. Homeless children are children who work and also sleep on the street (either with family members or on their own). Street-working children are children who spend much of their time working on the streets for income or just to pass time but these children return to a home at night. Mere involvement in street activities does not necessarily make a child a homeless child. In these surveys most street children were found to be sleeping in households, and thus included in the household survey sampling frame. Note that for survey purposes the definition of a 'household' is not necessarily a nuclear family but is a group of people who live together in a building and share the same kitchen. Child-headed households are included in household survey samples.

The objective of frame development for homeless children was to identify and interview them in settings where they would likely sleep. In this context the concept of 'sleep-sites' was utilized, with the idea that all locations where homeless children might sleep would be compiled. Those locations would then comprise the sampling frame. As with the institutional component, the process of compilation was, again, to conduct systematic interviews with all public health, social services and law enforcement officials serving those cities, inquiring about all locations where children were known to sleep, such as under bridges, on rooftops, abandoned buildings and the like. A survey instrument was provided to facilitate this process, to be administered systematically to appropriate government officials, religious organizations and NGOs. Again, there is no real means of verifying the accuracy or completeness of the final list of sleep-sites – 43 in Blantyre and 39 in Kingston – that comprise the sampling frame. There was some evidence, however, that local expertise was not precise. Twenty-four of the 41 sampling sites identified in Kingston had no children present and were, in effect, out-of-scope for the frame. However, this discordance between the sampling frame and what was found in the field was largely due to the mobility of homeless children and fluctuations in where they slept.

The design of the homeless sample consisted of creating 'primary sampling units' from the sleep-sites by dividing them into time-segments of 6 or 8 hours each and covering a 24-hour period. This was done because a person might sleep at any time during a 24-hour day, not just at night. Thus, sleep-site 'A' might comprise 4 primary sampling units (PSUs), say, 6 a.m. to noon, noon to 6 p.m., 6 p.m. to midnight and midnight to 6 a.m. The sample plan was to select a sample of these PSUs and station interviewers at them during the prescribed time-interval. All persons present at the site or arriving during the time interval would be screened for age and homeless status. All persons found to be older than 17 would be excluded from the survey, and all persons 17 or younger who had slept in a household or institution the night before would also be excluded on the grounds that they were not truly homeless; these persons in fact had their statistical chances of being included in the household or institutional samples anyway. Finally,

an important feature of the sample design was to obtain a rough measure of size for each PSU prior to sample selection. For example, PSU 1 might have 20 children, while PSU 2 might have only 3. This information was to be used to stratify the sample and to assist in planning interviewer workloads.

In Blantyre, all street locations where children were known to sleep were divided in three eight hour time periods cover 24 hours (noon-8pm; 8pm – 4am; 4am – noon). However homeless children were difficult to find at night while they were sleeping. Thus for the Kingston survey the time periods for the street portion of the survey were shortened to three six-hour periods covering 18 hours (6 a.m.-noon; noon-6 p.m.; 6 p.m.-midnight)and the focus shifted to identifying children during the periods when they were awake and working. The identified children were then asked about where they had slept the previous night to determine their homeless status.

Because there were so few time-site PSUs in both Blantyre and Kingston, it was decided to include all of them in the survey. Interviewers were dispatched to each PSU and were instructed to interview every child already present or arriving at the site during the prescribed time interval. Thus, there was no sampling per se for the homeless sector. It was, in effect, a census of homeless children. Only 81 homeless children were identified in Blantyre and 44 in Kingston.

The small number of homeless children seems surprising. But the street survey only included children who slept on the street the night before the survey and did not include children who work on the street. The design of the survey was based on the concept that all children sleep somewhere, and thus to get a complete sample of children all sleep sites must be sampled. Many of the children who were located on the street responded that they slept in a home at night and that they were only working or hanging out on the street during the day. Those children who slept in a home were not interviewed in the street survey because their information would have already been captured in the household portion of the survey.

Observation in some large cities might suggest there are a lot of children on the street leading one to assume that indicators on children only collected through a household-based survey are biased and under-representative of the true child population. However, if, as was the case in both Blantyre and Kingston, the vast majority of these children are street-working children who sleep in households, then these children would in fact be included in a household-based sample.

Even in a city such as Kingston, which has a high number of street-working children, these children–while hustling, begging and working on the street during the day–in fact, return to a household at night to sleep. While Kingston no doubt has large numbers of street-working children, the actual number of homeless children is far smaller. This fact does not negate or invalidate the necessity of organizations such as Children First, which works with street- and at-risk-children. Clearly children who sleep in households, but work or hustle on the street during the day are extremely vulnerable and in need of protection and advocacy. However, from the limited perspective of data collection, the number of children that are missed in household surveys – i.e. who are sleeping on the street and are not sleeping in a household – is relatively small.

4. Survey Instruments

The questionnaire design of the household component was based on that of the AIDS Indicator Survey (AIS), implemented by ORC Macro. The AIS is a household-based population survey, which collects data used to monitor and evaluate national AIDS responses. These surveys use the same methodology and similar standard as the Demographic and Health Surveys which are also implemented by ORC Macro (see www.measuredhs.com).

Similar to the DHS, the AIS has different data collection instruments: a household survey and an individual survey (the DHS separates the individual surveys for men and women). The AIS household questionnaire includes a household schedule, which is used to identify eligible men and women (based on age – typically ages 15–49) for individual interviews and to obtain information on basic characteristics of the household and its members. Specifically, information is obtained on parental survivorship and residence, which provides the basis for the calculation of orphan-hood levels. In addition, indicators on care and support and on orphans and vulnerable children are included as part of the household questionnaire.

The AIS individual questionnaire, which is used to interview both women and men, obtains data on background characteristics, pattern of marital unions, age at sexual debut, patterns of sexual behaviour in the last 12 months, condom use, experience with sexually transmitted infections (STIs) and treatment response to self-reported STIs, knowledge and attitudes related to HIV, and coverage of HIV-testing.

While the AIS is implemented only in households, the OVC pilot survey consisted of three distinct components: a household survey, an institution survey and a street survey. Thus, instead of the two survey instruments that are used in the AIS, five questionnaires were used during the OVC Pilot Survey:

- A household questionnaire (for the household survey);
- An institution questionnaire (for the institution survey);
- A street questionnaire (for the time-location survey);
- An individual questionnaire (In Malawi: for all household members age 15–49 and for individuals age 15–17 living in institutions or in the street; in Jamaica for all household members age 15–24 and for individuals age 15–17 living in institutions or in the street);
- A child questionnaire (for all children age 12–14 living in households, institutions and in the street).

The **household questionnaire** was modified from the standard AIS household questionnaire, and included questions on basic demographic characteristics, education, basic material needs, parental survivorship for children 0–17, identification of chronically ill adults living in the household, birth registration, water and sanitation facilities, food security, support for chronically ill adults and for OVC, and anthropometry (height and weight of all children age 0–8 living in the household). This questionnaire was only administered to household heads.

The **institution questionnaire** was designed to collect information similar to that of the household questionnaire. It provided information on the children living in the institution,

including basic demographic information, length of stay at the institution, parental survivorship, siblings living at the institution, basic material needs, education and anthropometry.

Before the institution questionnaire was completed, a screening tool – the institution roster – was used to create a sampling frame from which eligible children living in the institution were selected. The institution roster collected the names and ages of *all* of the children living in the institution, as well as whether or not they slept in the institution the night before (*de facto* residents) or were usual residents of the institution (*de jure* residents). The administrator or another competent staff member of the institution responded for the roster and the institution questionnaire.

The **street questionnaire** consisted of basic demographic information, length of time spent living on the streets, survivorship of parents, food provision, basic material needs, education, and anthropometry. A simple screening tool – the street roster – was used to find out which children were eligible for the street questionnaire. The street roster asked the child's name, sex, how old the child was and where he/she slept the night before. All children under the age of 18 who slept neither in a household nor an institution the night before were eligible for the street survey.

The **individual questionnaire** for 15–49 year olds was modified from the standard AIS individual questionnaire and included questions on background characteristics, reproductive history, pattern of marital unions, age at sexual debut, patterns of sexual behaviour in the last 12 months, condom use, experience with and treatment of sexually transmitted infections (STIs), knowledge and attitudes related to HIV, circumcision status, coverage of HIV-testing, use of safe injections in the last 12 months, and for those under age 18, connectedness to one's caregiver and psychological health. The individual questionnaire was used for interviewing both men and women and was administered to all persons over age 15 in all three settings who were selected for the survey. In the institutions and on the street this included only persons aged 15–17.

In Blantyre, all household members age 15–49 were interviewed using an individual questionnaire. In Kingston, household members age 15–24 were interviewed using an individual questionnaire. The smaller age group in Kingston was used due to financial constraints and the recognition that most of the indicators being pilot tested were youth-related.

The **child questionnaire** was a short instrument that included questions on literacy and connectedness to one's caregiver and psychological health, which was used only with children age 12–14. In all three settings, all children age 12–14 were interviewed using a child questionnaire.

All survey instruments were developed by ORC Macro with technical assistance on the OVC questions provided by UNICEF headquarters. The survey instruments used are available at www.childinfo.org.

5. Calculating Representative Indicators: Are street surveys and institutional surveys necessary?

One of the objectives of the pilot test was to demonstrate how data from three separate and independent sample surveys could be combined to provide estimates for the total population. In the pilot surveys there were several hundred households (400 in Blantyre and 800 in Kingston) sampled with small probabilities of selection. On average, about 1 in 325 households were selected in Blantyre and about 1 in 310 in Kingston).[2] In both Blantyre and in Kingston, one out of every two of the institutionalized children were sampled – a 50 per cent sampling rate of children living in institutions. Questionnaires were completed for all children who reported they did not sleep in a household the night before the survey in both cities. This is considered to be a 'census' of the homeless children in the city.

To produce estimates for the combined totals of the three independent samples, the data from each one must be *weighted*, especially since they were sampled at different rates of selection. A survey weight is defined as the inverse of the probability of selection. Thus, in Blantyre where the household sampling rate was 1/325, the weight is – again on average – simply equal to 325. Similarly, in Kingston the average weight was 310. The weight for the institutional sector in both cities was 2, that is, the inverse of 1/2; and the weight for the homeless sector was 1, because no sampling was done. Each of these weights was then adjusted to account for non-response. The household sample weights were further adjusted to reflect sub-sampling rates when the latter were used to administer the individual questionnaires for men and for women. But to illustrate the estimation method we only need to show the procedure as though unadjusted weights were used, because the principle is the same. Thus, if x_a, x_b and x_c represent, respectively, the household, institutional and homeless sample frequencies of persons in Blantyre with a certain characteristic, the survey estimate for the total number of persons with this characteristic is the weighted sum of these values, as follows:

$$x = 325x_a + 2x_b + x_c.$$

An example of this calculation is shown in Table 1. Table 1 shows the weighted and unweighted number of children age 0–17 in Blantyre and in Kingston. In Kingston, for example, 770 children age 0–17 living in households were interviewed, compared to 601 children living in institutions and 43 children living on the streets. Using unweighted numbers, slightly more than 50 per cent of the children interviewed live in households. However, when weights are applied, the number of children living in households is

Table 1. Number of children age 0–17

	Unweighted total	Weighted total	Per cent of weighted total
Blantyre			
Households	769	246,590	99.81
Institutions	178	356	.14
Streets	81	103	.04
Total	996	247,049	100.00
Kingston			
Households	770	275,492	99.52
Institutions	601	1,285	.46
Streets	43	44	.02
Total	1,414	276,821	100.00

[2] The actual probabilities of selection were variable by cluster.

increased to 275,492 or 99.52 per cent of the total number of children identified. Thus in Blantyre less than two-tenths of a per cent of children lived outside of households and in Kingston slightly more than half a per cent lived outside of households.

It is clear that children living in households have an overwhelming effect on the proposed indicators and estimates from this survey. This effect is seen across all indicators and estimates. Table 2 shows the number of OVC age 0–17 by location. In Blantyre, 99 per cent of children classified as OVC live in households, while 0.5 per cent lives in institutions, and 0.1 per cent live on the streets. In Kingston, 98 per cent of children classified as OVC live in households, 2 per cent live in institutions, and less than 0.1 per cent live on the streets.

Table 2. Number of OVC[1] age 0–17

	Weighted total	Per cent of total
Blantyre		
Households	71,265	99.4
Institutions	356	0.5
Streets	103	0.1
Total	71,724	100.0
Kingston		
Households	68,597	98.1
Institutions	1,285	1.8
Streets	44	0.1
Total	69,926	100.0

[1] Expanded definition of OVC.

The impact that these weights have on indicators is as striking as it is predictable. Table 3 shows the percentage of children age 5–17 in Blantyre who have a pair of shoes. Seventy-two per cent of children living in households have a pair of shoes, while 65 per cent of children living in institutions and only 15 per cent of children living on the streets have a pair of shoes. However, when this figure is combined for all three settings, the result is unchanged from the household-only figure of 72 per cent.

A sensitivity analysis of the contribution of children outside of households on national indicators suggests that even if the number of children outside of households was double what was found in these pilot surveys, the number of OVC is still likely to comprise only 2 or 3 per cent of the total population of OVC. These numbers are statistically inconsequential relative to the number of OVC residing in households. It suggests strongly that, in other cities and countries where the situation is similar – that is, where the vast majority of street children are not homeless, but in fact sleep in households, and the number of institutionalized children is relatively low – it is not necessary to conduct surveys of institutional and street children when the objectives is to supplement household surveys for calculating indicators on OVC. The situation can be assessed relatively easily in a community using the street and institution rosters.

Table 3. Per cent of children age 5–17 who have a pair of shoes, Blantyre, Malawi 2004

	Per cent with a pair of shoes	Number
Households	72.3	170,743
Institutions	64.7	232
Streets	15.4	99
Total	72.3	171,074

While homeless children, and to a lesser degree those living in institutions, are far worse off as a whole than children living in households, the impact that the latter two groups have on calculating nationally representative indicators is negligible. Homeless children are vulnerable and warrant special interventions and surveys monitoring their well-being. However, to calculate nationally-representative indicators, it is not necessary to include homeless and institutionalized children in a sampling frame. In these settings a household-based survey is sufficient to collect data representative of the entire child population, including the entire OVC population.

6. Definition of children made vulnerable by AIDS

Background

There has been an ongoing debate on how to define 'vulnerable' when measuring the well-being of OVC. The definition was discussed at the Technical Consultation on Indicator Development for Children Orphaned or Made Vulnerable by HIV/AIDS in Gaborone in 2003 but no decision was reached. The conclusion of the consultation was that the definition should be decided based on the results of the field-testing of the OVC indicators.

This section presents the data available from the pilot surveys that inform this debate. The objective was to determine the most appropriate definition of OVC for creating consistent measures of indicators over time. It should be noted that the definition of OVC used for monitoring should not necessarily be used as criteria for implementing programmes; rather, the definition is proposed because it is a measurable proxy for identifying children affected by AIDS and it is feasible to measure it consistently over time.

In addition the definition should be a proxy for children affected by HIV and AIDS. It is not possible to know the HIV status of the parents at the time of the survey and thus it is not possible to precisely measure those children who are affected by HIV and AIDS. Long term morbidity and mortality among adults ages 18–59 is the most feasible measure of morbidity and mortality due to AIDS in a household survey. The criteria for classifying a child as vulnerable needs to be measurable through basic questions asked of a household head.

Although children who are living in poverty, are exposed to violence, or who live either on the street or in institutions are vulnerable by definition, they are not necessarily vulnerable due to AIDS. For the purpose of measuring children made vulnerable by HIV and AIDS, we do not include these vulnerable groups in the definition. This is not to say that the well-being of these children is not equally as important, or that programmes should not ensure that these children are reached by interventions; these groups of vulnerable children are merely beyond the scope of this measurement exercise.

Two proposed definitions of OVC

Two approaches can be taken to such a definition: one is more 'basic' and likely to include fewer children and the second is an 'expanded' version of the first because it identifies a larger proportion of children as vulnerable.

The **basic definition** includes:

- a child < 18 either of whose parents has died
- a child < 18 either of whose parents has been ill for 3 of the past 12 months

The **expanded definition** includes:

- a child < 18 either of whose parents has died
- a child < 18 either of whose parents has been ill for 3 of the past 12 months
- a child < 18 who lives in a household in which an adult (18–59) has died during the past year and was ill for 3 of the 12 months before the death

- a child < 18 who lives in a household in which an adult (18–59) has been ill for 3 of the past 12 months

'Chronically ill' is defined and explained to the respondents as when an individual is too sick to participate in household chores or activities.

Naturally, children who are infected with HIV should be included in the definition when it is feasible to do so with the measurement tools. In most surveys, however, the HIV status of the child will not be known at the time of the survey and thus questions on support and their well-being can not be targeted at these children.

The pilot surveys also examined whether children living in child-headed households and in elderly-headed households should be included in this definition. The two pilot surveys found very few child-headed households (0 in Kingston and 5 in Blantyre) and very few children living in elderly-headed households (1% in each city) *that were not already captured in the other categories*. For example children living in child headed households are very likely to be orphans and are thus already captured in this definition. Children in elderly headed households could be living with a grandparent for numerous reasons. If children are living with grandparents because the parents are no longer physically able to look after the children, they are likely to fall into the category of having a chronically ill parent.

The basic definition is simpler to collect, however, the expanded definition includes children who are vulnerable because an adult who was/is a primary caregiver or income generator for the household is ill or has died. In the pilot survey, data were collected to measure these two possible categories.

The definition of vulnerable is important for numerous reasons; but most of all because these are the children that are in the crises period of transitioning to losing an adult in their life. On the other hand, orphans could have lost their parent a month before the survey or 10 years before the survey. Their well-being could have changed drastically since the death of the parent and thus measuring their well-being can be diluted by the different proximity in time to the loss of their parent. It is important therefore to disaggregate the data by orphans and by vulnerable children (regardless of their orphan status) to untangle those children who are in a crises period to those children that might have been orphaned many years earlier.

Are children in the expanded definition already covered in the basic definition?
The basic definition requires less data be collected and might be a preferable option if there were little difference between the basic and expanded definition. For example if most of the children categorized as vulnerable in the expanded were categorized similarly in the basic definition, there would be no need for the extra data. The children in the pilot surveys were mapped by the different criteria for vulnerability to see where they overlapped.

Of the 769 children in households in the Blantyre survey, 11 per cent were classified as vulnerable under the expanded definition and 6 per cent were classified as vulnerable under the basic definition. Similarly of the 770 children in households in the Kingston survey, 16 versus 8 per cent were classified as vulnerable in the expanded and basic definitions, respectively. In

both cities the number of children defined as vulnerable doubled using the expanded definition. The increased number of children captured with the expanded definition will improve the stability of indicators on vulnerable children. We might have captured more children who are not OVC but it would be better to catch more children and have the indicators be diluted than to miss many children who are vulnerable.

A larger proportion of the vulnerable children were due to ill adults in the household in Kingston as compared to Blantyre (38 per cent in Kingston versus 15 per cent in Blantyre, see Table 4). Recall that interviewers are instructed that chronically ill means that the respondent was too sick to work or do normal activities around the house during the period. Using this definition in a low-HIV prevalence setting probably captured a large number of adults who had other chronic diseases common in more developed settings – diseases that might be less debilitating. In low-HIV prevalence settings 'chronically ill' fails to be a useful proxy definition for people who are ill because of AIDS.

Table 4. Vulnerability criteria for children in households

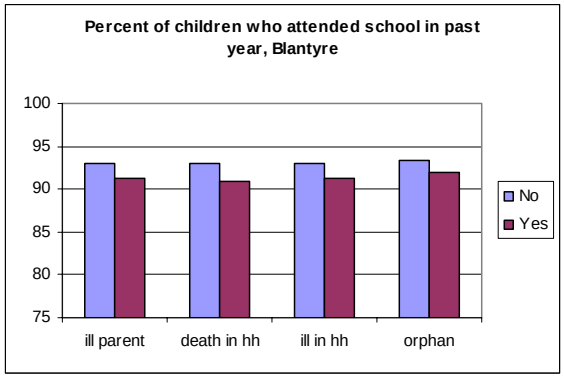
	Blantyre			Kingston		
Vulnerability criteria	Number (unweighted)	Per cent of vulnerable children	Per cent of all children	Number (unweighted)	Per cent of vulnerable children	Percent of all children
Ill parent	12	14		17	14	
Ill parent and ill adult in household	33	38		46	37	
Ill parent and household death	0	-		0	-	
Basic definition	-	-	6	-	-	8
Ill adult in household, household death, and parent ill	3	3		0	-	
Household death	23	26		14	11	
Adult ill in household	13	15		47	38	
Ill adult in household and household death	4	5		1	1	
Expanded definition			11			16
Total vulnerable children	88	100		125	100	
Vulnerable children also classified as orphaned	48			11		
Number of all children in households	769			770		

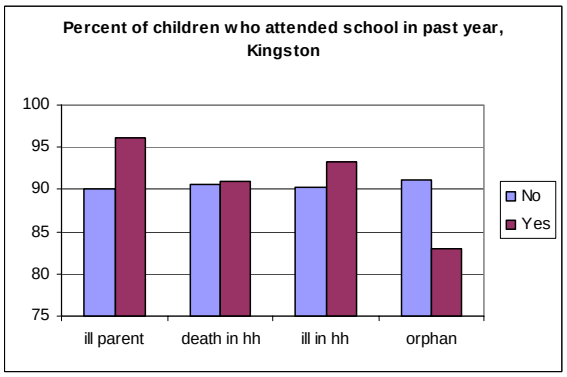
Shaded rows show the additional categories for the 'expanded' definition.

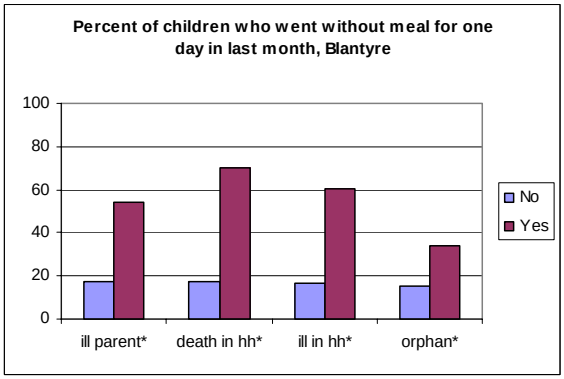
Are children with sick adults in their households or who experienced adult deaths in their households as vulnerable as children with chronically ill parents?

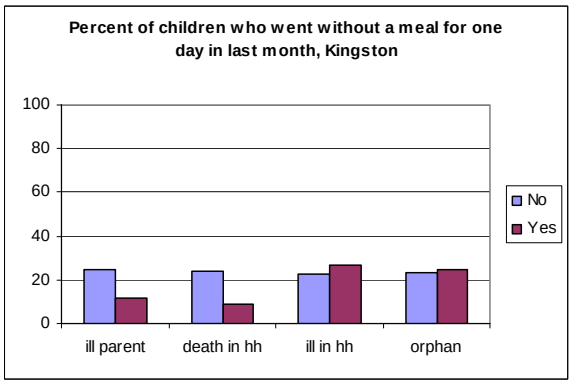
Figures 1a-h show the situation of the children in the survey by the various vulnerable criteria. These children are tabulated regardless of orphan status or other vulnerabilities. For example a child with a death in the household could also be an orphan or have a chronically ill parent. Four indicators are used here to portray the situation of these children: school attendance, household food security, basic material needs, and psychosocial well-being. (These indicators are more fully described in the later chapters.) Those categories with an asterisk (*) are statistically significant at the 0.05 level.

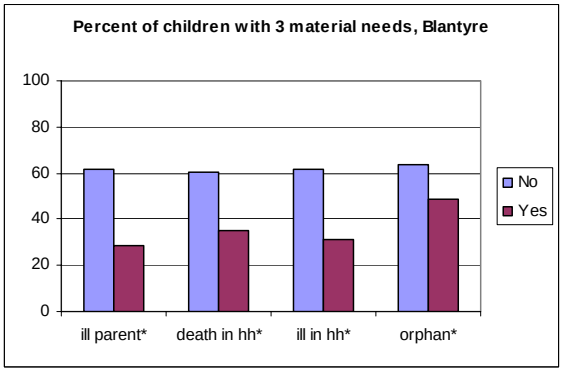
Figures 1a-h: Basic well-being of children with different vulnerability criteria
Comparisons noted with an asterisk (*) are statistically significant at the 0.05 level

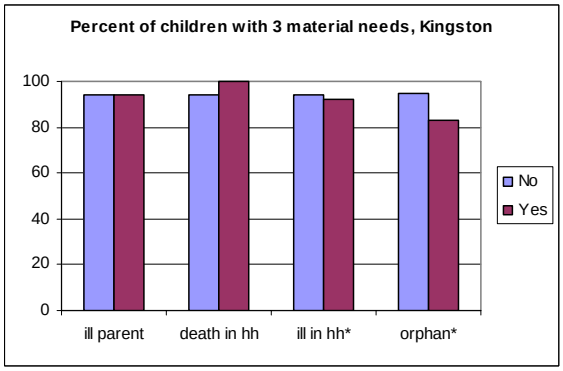


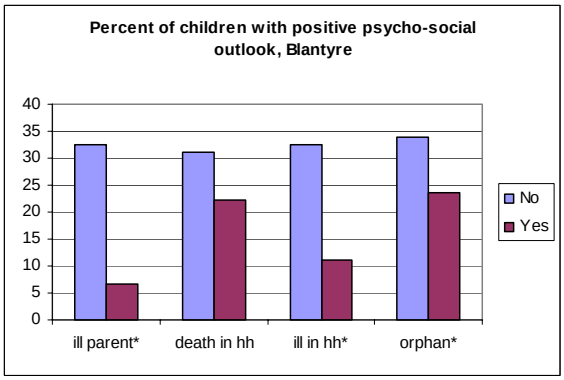


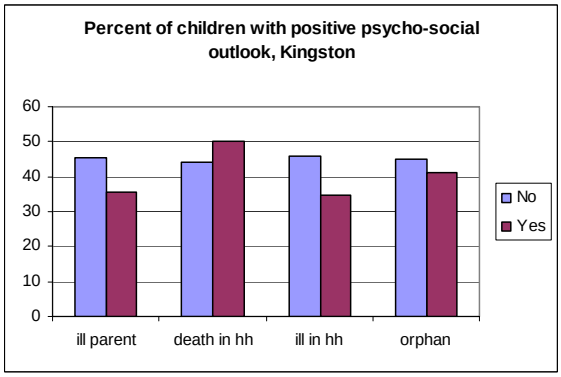












Children classified as vulnerable because they have a chronically ill parent, who live in a household with a chronically ill adult or who live in a household where an adult has recently died, have worse outcomes than other children. In most cases, orphans have better outcomes than children who are vulnerable. This is probably because orphans could have suffered the death of a parent any time over their life span, while the vulnerable criteria are related to events in the past year.

The data from Kingston are less conclusive. This could be because the diseases that are making adults 'chronically ill' are less debilitating, such as some forms of diabetes or high blood pressure.

In Blantyre, children in households with a chronically ill adult or in households where an adult died have outcomes similar to children with chronically ill parents. This would suggest these children should be included in the definition because 1) their situation is due to an adult death or morbidity and, given the high HIV prevalence in Blantyre, is likely to be due to AIDS, and 2) these children appear to be vulnerable, and 3) it is possible to identify these children easily in our current tools.

The striking finding, that vulnerable children were significantly worse-off than orphaned children is important to note. A key recommendation from the pilot surveys is that indicators should be tabulated separately for vulnerable children and for orphans; all indicators should be presented by vulnerability status, regardless of orphan status.

An expanded definition

The expanded definition of vulnerable (including chronically ill parent, chronically ill adult in household, or adult death in household) is likely to capture a larger proportion of children who are affected by HIV or AIDS. The basic definition excluded about 50 per cent of the vulnerable children. The increased number of children covered in this definition will also allow for more accurate/stable measures of the well being of these children.

In order to avoid situations where the definition captures children made vulnerable by illnesses other than AIDS, the proposed definition should only be used in high-HIV prevalence settings (above approximately 5 per cent HIV prevalence among the adult population).

Finally, the expanded definition poses little additional burden to data collectors because the additional questions needed to capture whether an adult in the household has died are relatively straightforward. Chronically ill status is already asked for all adults in the households in order to define chronically ill parents.

7. OVC Indicators

The indicators that were tested in these pilot surveys were developed for the *Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS*. The purpose of the guide and the choice of indicators are described in that document.

This chapter provides a brief review of the challenges and decisions made on the proposed indicators. We provide a handful of the results to explain the decisions made about the indicators. The full results and analysis have been summarized in reports produced by the UNICEF offices of Malawi and Jamaica.

The pilot surveys evaluated the following indicators for monitoring national level responses to OVC:

- Basic Material Needs – the ratio of OVC that have three minimum basic material needs for personal care provided by their families to non-OVC with the same items. In the case of Blantyre and Kingston, the material needs which were selected were (1) a blanket/something to cover him/her at night while sleeping; (2) a pair of shoes; and (3) at least two sets of clothing.
- Malnutrition – the ratio of the per cent of underweight OVC to the per cent of underweight non-OVC
- Food security – the per cent of households which are food insecure.
- Psychological health – the ratio of the per cent of OVC with an adequate score for psychological health to the per cent of non-OVC with an adequate score for psychological health.
- Connection with an Adult Caregiver – the per cent of orphans with a positive connection with their primary caregiver.
- Quality of institutional care – The per cent of children living in institutions that comply with a core set of standards of institutional care that are internationally acceptable in terms of environment, vision, values and administration as alternatives to family-provided shelter.
- Children outside of family care – the per cent of all children living outside of family care.
- Succession planning – the per cent of children for whom the chronically ill parent or primary caregiver has identified a standby guardian who will take care of the child in the event of premature death.
- Sibling separation – the per cent of orphans living with all of their siblings under the age of 18
- External support for orphaned and vulnerable children – the per cent of OVC whose households receive free basic external support in caring for the child.

- External support to households with chronically ill adults – the per cent of households who receive free basic external support for caring for a chronically ill adult

Basic material needs. As the AIDS epidemic progresses it is critical for governments to ensure that families have the ability to provide for children's basic needs. An indicator on basic material needs assesses the ability for families to meet those needs. This indicator measures poverty to some extent, but goes further to measure the impact of that poverty on individual children. Other basic needs such as food, education and health are measured in other indicators.

Questions were asked for all children ages 5–17, about whether they have the following three items: a blanket (or 'something to cover him/her up at night when sleeping'); a pair of shoes; and at least two sets of clothing. These questions were either asked to the head of households or to a responsible adult (in the institutions) or directly to the children if they were homeless.

A number of concerns were raised about this indicator before and during the pilot surveys. One concern was that material needs differ by region or country. In a tropical climate where the temperature rarely falls below 20 degrees Celsius, a cover or blanket might not be needed for warmth. However, an exit survey of respondents in the Kingston survey found that the majority of respondents who reported not to have a blanket, did not have one because they did not have the resources to acquire one.

Respondents might also not understand how to respond if an item is shared. It was pointed out that it is common for children in Malawi (and elsewhere) below the age of 12 to share a blanket as they share a mat. Materials that are shared should be counted in the numerator as the child has access to the item.

The indicator also does not specify the quality of the items. For example, should a pair of shoes with only a partial sole count as meeting the child's basic needs? Whether an item meets a level of quality is not determined by these questions. The interviewers will have to subjectively decide whether an item should be counted as meeting the child's needs.

In both Blantyre and Kingston this indicator showed expected differences by background characteristics. (See Table 5 and Figures 1e and 1f.) In Blantyre, 50 per cent of the children on the street had none of the basic material needs. While in households 5 per cent of children were found not to have the basic material needs.

This indicator appears to be a straight forward and useful measure of a child's material well-being. It was recommended as a core indicator for the monitoring and evaluation guide.

Table 5. Basic material needs

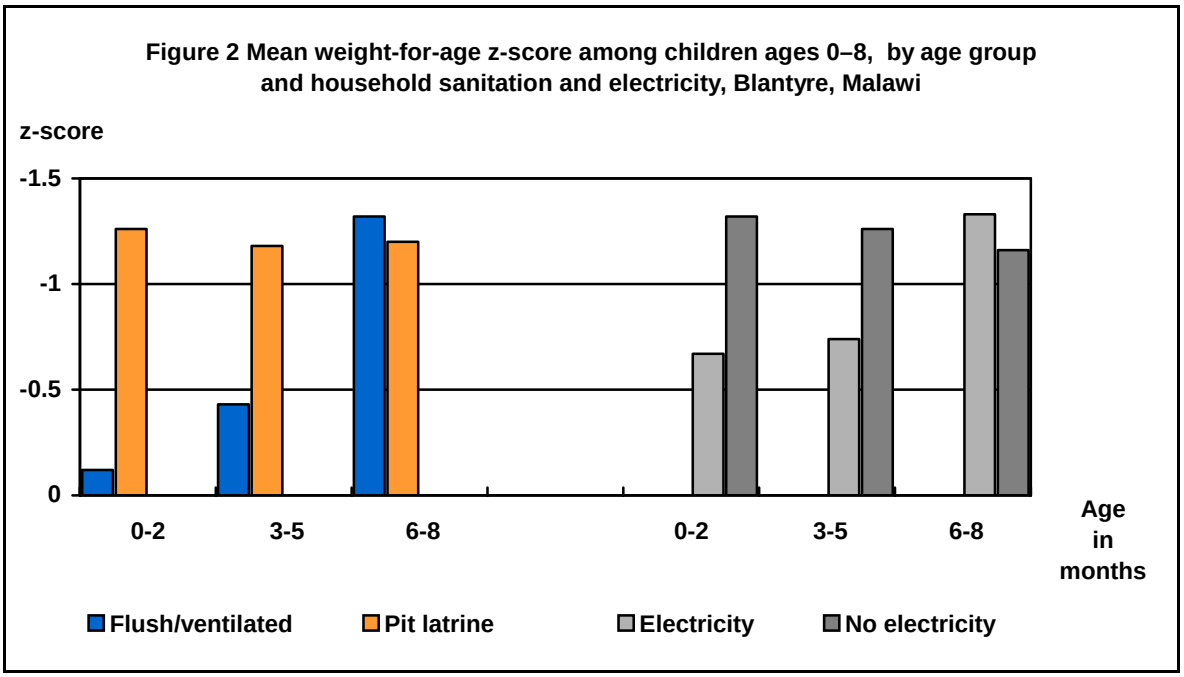
Per cent of children (age 5–17) who have three minimum basic material needs for personal care, Blantyre, Malawi 2004.

	Blanket	Shoes	2 sets of clothing	All three	Clothing and shoes	None	Number of children W	Number of children U
Setting								
Household	71.6	72.3	91.3	60.5	70.6	5.4	170,743	508
Institution	86.2	64.7	79.3	60.3	61.2	12.1	232	116
Street	15.4	15.4	42.3	3.8	11.5	50.0	99	78
OVC composition								
Orphan	55.9	66.5	89.5	50.0	65.4	9.0	50,945	275
Vulnerable (expanded)	42.6	55.7	88.9	32.5	55.6	10.9	20,981	255
OVC (expanded)	56.4	62.5	89.7	46.6	61.5	7.7	60,297	365
Non OVC (expanded)	79.8	77.6	92.1	68.0	75.4	4.2	110,777	337
Total	71.6	72.3	91.2	60.5	70.5	5.4	171,074	702

W = weighted, U = unweighted

Malnutrition. One of the key variables to measure the healthy outcome of children is to ensure that they are growing adequately and getting the proper foods. A basic ratio comparing malnutrition rates of OVC to those of non-OVC was suggested for this assessment. The number of orphans below age five captured in surveys is usually too few to calculate a reliable estimate of malnutrition. To overcome this limitation the pilot surveys collected data from children up to and including age 8. Beyond that age the standard data to which the anthropometry data are compared are no longer available (once children reach puberty their growth patterns are less standard and thus no standard comparison data are available).

The data from the two pilot surveys were analyzed by researchers at Tulane University to see how the malnutrition data could be used effectively (Rivers and others, 2006). The analysis looked at socio-economic variables associated with malnutrition and found that although the higher malnutrition was associated with higher socio-economic status for children 0–5, the association was not evident for children 6–8. Adding the age group 5–8 to the standard indicator increased the sample size but diluted any differences among the children. Figure 2 below shows underweight z-scores for children 0–2 and 3–5 and 6–8 by socio-economic variables. (A z-score of -1 means that the child was at least one standard deviation below the standard weight-for-age level for that age group.) For children 6–8 the expected difference by socio-economic status do not exists. Thus it is not useful to add the older age group to get a larger sample of OVC.



Since most surveys collect data on anthropometry in any case, this indicator remains as a core indicator. However, it is recommended to only calculate the ratio when surveys have a large enough sample of OVC among children 0–4. Appropriate caution should be taken when interpreting or comparing the indicator. Further research is needed for alternative measures of health among OVC.

Food security. Before a child becomes malnourished, he/she is likely to live in a home that is considered food insecure or has inadequate resources for food. This is again a sign that households are no longer able to provide for children and assistance is needed.

Food security within a household was assessed through a series of questions about behaviours and experiences that are known to characterize households having difficulty meeting their food needs. These questions follow a documented pattern of food difficulties among households. The questions asked were as follows:

In the last 30 days,

- Did you ever cut the size of your meals or skip meals because there was not enough food or money to buy food?
- Did you ever eat less than you felt you should because there was not enough food or money to buy food?
- Were you very hungry but did not eat because there was not enough food or money to buy food?
- Did you ever not eat for the whole day because there was not enough food or money to buy food?
- Did you ever cut the size of your child(ren)'s meals because there was not enough food or money to buy food?

- Did the child(ren) living in your household ever skip meals because there was not enough food or money to buy food?
- Was/were the child(ren) living in your household ever hungry but there was not enough food or money to buy food?
- Did the child(ren) living in your household ever not eat for the whole day because there was not enough food or money to buy food?

Since any adult who was a usual resident of the household could respond to the questionnaire, the questions on food security might not always be answered by a person who is in a position to know what all individuals in the households had eaten over the prior month or how food allocation and purchasing decisions were made.

The indicator measures the food security of the household and not the individual child as most other indicators. Thus, the food security status of the orphans and vulnerable children is not actually measured but rather the food security status of the household as a whole. This enables a comparison to be made between households with OVC vs. households with non-OVC children, but not a comparison between orphans and vulnerable children and other children. The indicator is thus unable to take into account differences in food security status that might exist within the household unit itself.

It is important to consider what constitutes a 'meal.' In Malawi, for example, a considerable number of people do not consider certain foods to comprise a meal. For example, for many people in Malawi, a serving of food has to include *nsima* (a dish prepared using maize flour and water) in order to be considered a meal. Therefore, eating boiled potatoes with beans or rice would not be regarded as a meal, while eating *nsima* with beans would be. In Jamaica the proportion of households reporting to be food-insecure was quite high. This was surprising given the relatively more affluent population in Kingston. This again could potentially be due to different interpretations of what constitutes a meal.

Researchers from Tulane also analysed these data to look at the quality of this indicator. They found this indicator to be internally valid using t-tests and Cronbach's Alpha Reliability estimations (results not shown). This indicator correlated easily with poverty indices, anthropometry and orphan status in Blantyre (see Table 6). The indicator did not correlate well in Kingston. This is potentially because of the difficulty in using such an indicator in a 'transitional' country, with relatively little food security problems. There was some evidence in Kingston that households with OVC were more likely to be food insecure than households with no OVC as were female headed households.

Table 6. Food security

Per cent of households with children age 0–17 years old that are food insecure, Blantyre, Malawi 2004.

	Food secure	Food insecure with no hunger	Food insecure with moderate hunger	Food insecure with severe hunger	Don't know/missing	Total	Number of households with children age 0–17	
							W	U
Age of HH head								
<18	10.9	31.5	21.9	35.7	0.0	100.0	1,637	6
18–54	45.5	15.5	3.1	34.9	0.9	100.0	76,778	233
55+	38.1	20.2	15.5	26.2	0.0	100.0	12,645	39
Sex of HH head								
Male	46.3	16.2	5.4	31.1	1.0	100.0	74,043	229
Female	33.1	17.7	4.2	45.0	0.0	100.0	17,017	49
Affected households								
Households with at least one OVC	38.4	13.8	6.2	41.5	0.0	100.0	38,968	113
Households with no OVC	47.9	18.5	4.4	27.8	1.4	100.0	52,092	165
Total	43.9	16.5	5.2	33.7	0.8	100.0	91,060	278

W = weighted, U = unweighted

Psychological health. Assessing psychosocial well-being of children orphaned and made vulnerable by AIDS is complicated although a necessary measure of the situation of children who have dealt with the emotional toll of the HIV epidemic. Attempts to measure children's psychological well-being is not a new endeavour, however, most of the research on psychological measurement has been done in western countries and applying this research to other cultures is difficult. Among many of the challenges to developing this indicator are the subjectivity of the measure, cross-cultural function-ability, and creating a standard quantitative measurement tool.

All children age 12–17 were read a series of statements and asked whether or not they 'strongly agreed, agreed, disagreed, or strongly disagreed' with the statements:

- I am happy
- I feel stressed and worried
- I feel good about myself
- My future looks hopeless to me
- I am able to do the things I need to do in my daily life (such as school, work, etc.)
- I want to be alone these days
- My health is good
- I get into fights
- I have hope that things will turn out all right for me

The responses were measured on a four-point scale with one representing 'strongly agreed' and four representing 'strongly disagreed'. Through observations and talking with interviewers during the field work, it was not certain that respondents grasped the concept of the four levels of

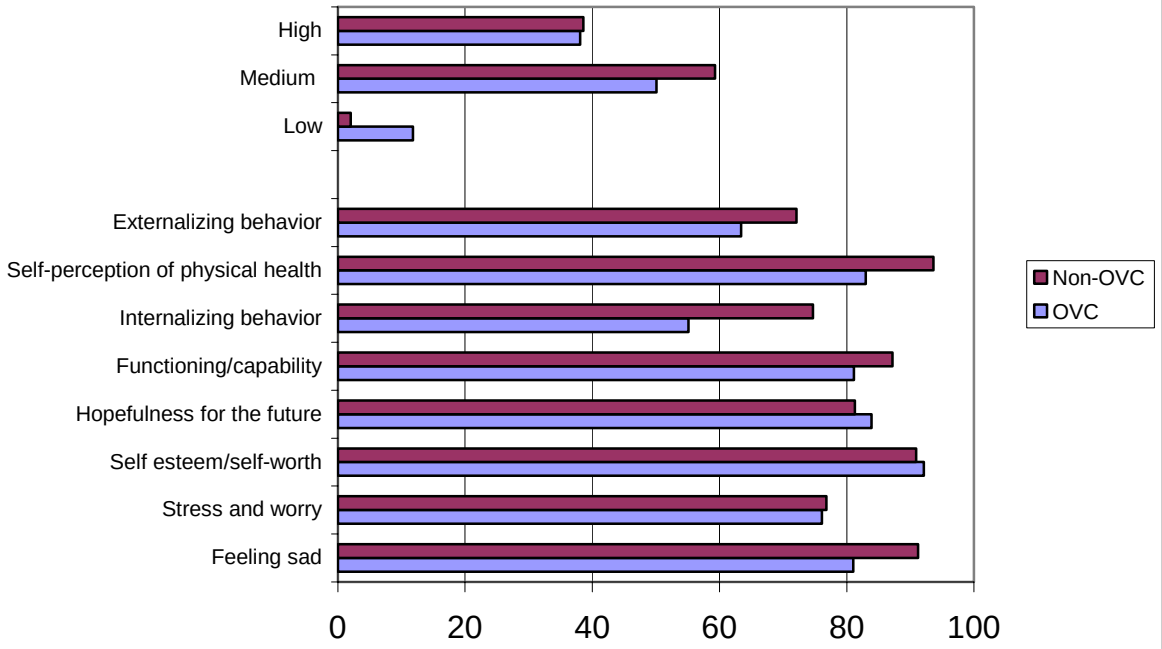
answers. For example, it was often answered as a yes or no question, the respondent either strongly agreed or strongly disagreed. In addition, asking questions that require ranking the answers were somewhat problematic if the respondent is required to verbally give a response without visualizing the four options. A recommendation that from the pilot surveys is to create a card on which to show a visualized response to the interviewees (such as faces showing different levels of happiness) when asking such questions.

A number of the concepts in the questions above could have various meanings in different cultural contexts. For example discussions with interviewers in Kingston suggested that 'happy' was associated with a person's financial situation and less so with their emotional outlook. However conducting qualitative investigations to better understand the language used in these questions might not be feasible for a large household survey. In addition changing the wording for each survey would change the meaning of the statements hampering the interpretation and the comparability of the data.

Additional research is underway on how to simplify and revise this indicator. For now, the indicator remains in the M&E guide as an additional indicator, but is listed as 'under development.'

Results from Blantyre are shown in Figure 3. Only a few of the questions showed significant differences between OVC and non-OVC. Overall OVC were more likely to have low psychological health scores. A Cronbach's Alpha reliability estimation showed fairly weak consistency among the components of the indicator suggesting that the variables were not measuring a similar construct.

Figure 3. Percent of children who responded positivly to questions measuring psychological health and psychological health score, Kingston



Connection with caregiver. A positive, emotional, stable relationship has been shown to be one of the strongest protective factors for child and adolescent development. Adolescents who perceive to have this relationship with a primary caregiver have been shown to be better off in numerous settings in various countries. An indicator to measure this connection was developed with researchers from the University of Tennessee.

All children age 12–17 were asked "what one adult do you spend the most time living with?" The adult identified is intended to be a proxy for the child's caretaker. The child was read a list of activities and asked if the caregiver did the following things 'not at all, hardly ever, sometimes, often, or very often:'

- Support and encourage you
- Show you affection
- Comfort you
- Understand you
- Give you advice or guidance
- Give you money
- Have open communication with you
- Support you in your school work
- Give you attention and listen to you
- Praise you
- Respect your sense of freedom
- Trust you
- Provide for your necessities
- Buy you things
- Spend time with you

One potential problem is that the phrase 'what one adult do you spend the most time living with?' often does not accurately elicit a child's caretaker. For example, if a child is in school, he may interpret the question to be asked of his teacher (i.e. the adult he currently spends the most

time with) rather than his mother (i.e. his actual primary caregiver.) A more directed wording of the question may help to reduce this confusion.

Analysis of the data collected for this indicator was carried out by researchers at the University of Tennessee. They found that the 15-item connection with caregiver scale represents at least two, relatively independent sub-dimensions: support and provision of resources. However after statistical analysis they found that each of these sub-dimensions is adequately measured with three items.

Further validations of the full 15-item scale will be conducted in 2005 by the WHO. Once analyses of those data sets are completed, a final decision will be made about the structure and item content for measuring this indicator. If it is not possible to include all 15 items in a scale, then it is recommended that 6 items (3 for support – comforts me, has open communication with me, trusts me; and 3 for resources – provides for my necessities, gives me money, buys me things) be used, and analyzed separately, i.e., separate scales for support and resources.

Table 7 shows that the sex of the child is associated with strong connection to an adult care giver in Kingston. Age also appears to be associated with the connection to the caregiver.

Table 7. Connection with an adult

Per cent of children 12–17 living in households that have a positive connection with the adult they spend the most time with, Kingston, Jamaica 2004

	Very weak connection (14–24)	Weak connection (25–35)	Intermediate connection (36–48)	Strong connection (49–59)	Very strong connection (60–70)	Total	Number of children	
							W	U
Age								
12–14	0.9	3.2	13.5	35.3	47.1	100.0	67,749	107
15–17	2.8	4.1	22.8	39.0	31.3	100.0	69,075	51
Sex								
Male	3.2	4.0	20.6	41.7	30.6	100.0	62,138	71
Female	0.8	3.4	16.2	33.4	46.2	100.0	74,686	87
OVC composition								
Orphan	0.0	0.0	30.3	39.0	30.7	100.0	15,960	17
Vulnerable (expanded)	0.0	0.0	40.8	27.1	32.1	100.0	34,689	32
OVC (expanded)	0.0	0.0	36.1	30.8	33.2	100.0	41,289	43
Non OVC (expanded)	2.7	5.2	10.5	39.9	41.7	100.0	95,534	115
Total	1.9	3.6	18.2	37.2	39.1	100.0	136,823	158

W = weighted, U = unweighted

Quality of institutional care. There is much concern about the increasing numbers of orphanages that are developing as a result of the AIDS epidemic. Ample evidence suggests that children are better off staying in family care (Frank and others 1996 and Tolfree, 2003). However, when there are no options, and a child ends up in an institution, measures of the quality need to be in place to ensure the well being of children in the institution. An indicator was proposed to measure the quality of the institutions covered by the survey.

The indicator assesses whether the institution is meeting basic standards of care. Questions are asked of the director, or a responsible head of the institution, for every child between the ages of 5–17. The questions include the number of children who:

a) are attending school in a mainstream education setting,
b) have had their 'individual care plan' reviewed within the last 3 months, and
c) who have had contact with a parent or family member in the last 3 months.

There were a number of difficulties with this indicator during the pilot surveys. The type of institution affected the responses that were given. Some institutions were juvenile detention centres, which limit contact with family and do not allow attendance within mainstream education settings. Thus the methodology of the surveys and the indicator proposed were not necessarily compatible. Also this indicator did not cover the important and complex needs of younger children.

There were a number of definitional issues about what was 'mainstream education,' or what level of interaction was considered contact with a parent. Also the individual care plan was not a standard tool used in all institutions. The indicator was dropped from the guide because of the need for a complete revision of the indicator. Further research into how to better measure formal care is being conducted by UNICEF.

Children outside of family care. Among one of the first signs that families are not able to support the children that are orphaned due to AIDS is an increase in children resorting to living on the street or in institutions. Monitoring the number of children in these settings will provide evidence on the ability for communities to support children affected by AIDS.

Methods for how this indicator was collected are described in Chapter 3 of this report. The information to estimate this indicator was available directly from the institutional roster and the street roster. Thus a full survey of children outside of family care was not necessary to estimate this indicator. It also does not need to be merged with a household survey as the denominator for this indicator can come from national census estimates of the number of children under age 18.

The weighted results (see Table 1) show that in Blantyre, an estimated 356 children lived in institutions and 103 children were homeless. While in Kingston an estimated 1,285 children lived in institutions and 44 children were homeless. In both cities less than 1 per cent of children live outside of family care.

This indicator is a core indicator in the M&E guide and is thought to be critical for measuring the ability of families and communities to provide homes for children orphaned by AIDS.

Succession planning. One way for parents to ensure the well-being after they have died is to appoint a guardian for the child. In most countries, family laws stipulate a process to appoint a guardian. This 'legal guardian' may be an executor of a will, or a decision maker, and could, but not necessarily, be in a position to provide care in a family environment. This indicator seeks to identify a person who would provide direct care and support to a child. The identification of a caring guardian involves other processes that together comprise succession planning. For children made vulnerable by AIDS, this is particularly helpful, because it allows HIV-positive

parents, while they are identifying guardians, to deal with disclosure of their status to their children, help prepare the children for the future, discuss family property with them, and seek the children's assistance during the time of parental illness.

Mothers or primary caregivers of each child were asked if she/he had identified a person with whom the child could live if she/he was not able to care for the child. In Blantyre[3] only 38 per cent of caregivers had appointed a potential guardian. This varied by age of the caregiver with older caregivers less likely to have designated a guardian (see Table 8).

Table 8. Succession planning

Per cent of men and women age 15–49 who identify themselves as a caregiver of a child or children under 18 and per cent distribution of caregivers who have identified a standby guardian who will take care of the child in the event of premature death, Blantyre, Malawi 2004

	Primary caregivers for children under 18	Number of adults 15–49		Made arrangements in event caregiver is sick or not able to care for children				Number of primary caregivers	
		W	U	Yes	No	Unsure	Total	W	U
Age									
15–24	23.8	141,530	400	43.2	56.8	0.0	100.0	33,676	96
25–34	39.7	88,953	247	39.2	59.1	1.7	100.0	35,321	101
35–49	66.2	51,387	146	30.5	69.5	0.0	100.0	34,002	95
Sex									
Male	32.6	142,281	400	36.2	63.2	0.6	100.0	46,337	132
Female	40.6	139,589	393	38.8	60.7	0.6	100.0	56,662	160
Health status									
Chronically ill	35.1	9,098	25	0.0	100.0	0.0	100.0	3,197	9
Healthy	36.6	272,772	768	38.8	60.6	0.6	100.0	99,802	283
Total	36.5	281,870	793	37.6	61.8	0.6	100.0	102,999	292

W = weighted, U = unweighted

Orphans living with siblings. This indicator assesses family capacity and community capacity to keep orphan siblings together in one household. Generally, sibling connections and attachments are even closer than usual when there has been inadequate parental care and nurture. Helping siblings remain together on the death of their parent(s) is therefore another way of strengthening orphans' ability to cope. Many extended families disperse orphaned siblings among different households to share the cost of their care. Interventions that enable families to keep siblings together help these children recover from their loss, support one another and remain in their own community. Siblings who are living together in foster care tend to have fewer emotional and behavioural problems than those who are living separately.

The head of the household was asked whether all biological siblings (under age 18) of each child live in the household. The indicator was limited to biological brothers and sisters to ensure the indicator was collected consistently and to ensure the relatedness of the children.

[3] This information was not collected in Kingston, as the questionnaires were limited to respondents age 15–24.

Separation of siblings is often a result of life processes, and eventually happens to most children. It is therefore important to exclude these 'natural' separation events from the forced separation due to orphanhood during childhood. Siblings who are separated due to marriage or further schooling should therefore be excluded. By limiting the focus of the siblings to under age 18, most of the bias will be avoided.

In Blantyre, only 8 per cent of all double orphans were living with all of their siblings (see Table 9); while 40 per cent of paternal orphans were still living with all of their siblings under age 18. This indicator could also be calculated for whether the child was living with at least one of their siblings. Table 9 shows that in institutions 48 per cent of children are living with at least one sibling.

Table 9. Orphans living with all siblings

Households				Institutions			
Among orphans age 0–17 living in households who have at least one sibling under the age of 18, the percent who live with all their siblings				Among children age 0–17 living in institutions who have at least one sibling under the age of 18, the percent who live with one or more siblings			
	Living with all siblings	Number of orphans with siblings			Living with any siblings	Number of children with siblings	
		Weighted	Unweighted			Weighted	Unweighted
Age				**Age**			
0–4	8.4	3,445	9	0–4	46.7	60	30
5–9	29.8	12,045	31	5–9	72.7	44	22
10–14	23.8	15,749	45	10–14	51.5	66	33
15–17	63.4	4,560	12	15–17	24	50	25
Sex				**Sex**			
Male	30.5	17,328	46	Male	31.3	128	64
Female	28.3	18,471	51	Female	71.7	92	46
Orphan status				**Orphan status**			
Not orphaned	-	-	-	Not orphaned	28.6	14	7
Double orphan	7.8	7,407	21	Double orphan	60.9	92	46
Maternal orphan	11.1	5,231	15	Maternal orphan	40.9	44	22
Paternal orphan	40.4	23,161	61	Paternal orphan	36.4	44	22
Total	29.4	35,799	97	Total	48.2	220	110

External Support. Programmers need to know the extent to which households caring for an orphaned or vulnerable child and caring for a chronically ill person has contact to a network of providers. Support is most likely to be consistent and sustainable if it is provided by community based organizations or government agencies. Two indicators were proposed to measure the extent to which households are reached by these networks.

Indicators CS9 and CS10, as defined in the *Guide to Monitoring and Evaluating HIV/AIDS Care and Support* (WHO 2004), look at external support which households receive in caring for the

chronically ill (CS9) and OVC (CS10). Chronically ill adults are defined as people age 15–59 who have been ill for 3 or more of the past 12 months. This is used as a proxy for adults who are sick with AIDS. Adults who were ill for 3 or more months before dying within the past 12 months are also included in this indicator.

External support for the chronically ill is defined as:

- health care and supplies;
- emotional and psychological: counselling from a trained counsellor, companionship and emotional or spiritual support; and
- other social support, including socioeconomic (clothing, extra food or financial support) or instrumental (help with household work, training for a caregiver or legal services).

External support for orphans and vulnerable children is identical to the above with the addition of school fees and school-related assistance for children age 5 and older.

External support is further defined as being free of user charges and coming from a source other than friends, family or neighbours unless they are working for a community-based group or organization. This indicator does not measure the needs of the household or the OVC. Additional questions could be added to measure expressed needs of families caring for orphans. The indicator implicitly suggests that all households with orphaned and vulnerable children need external support. Some orphaned and vulnerable children are more in need of external support than others. Therefore it is important to disaggregate the information by other markers of vulnerability such as socio-economic status of the household, dependency ratio, head of the household, etc.

As currently defined in the *Guide to Monitoring and Evaluating HIV/AIDS Care and Support*, the two care and support indicators use as a numerator the number of OVC or chronically ill who received ALL of the above listed external support. In response to the unknown need of households for support, this indicator has been modified for the OVC M&E guide to be ANY support. This is a better measure of whether the household is connected to a network of providers.

As can be seen in Tables 10 and 11, when the indicator is calculated based on ALL forms of external support, no child in either country is considered to have received external support. When the indicator is calculated based on ANY form of external support, 14 per cent of children in Blantyre and 4 per cent of children in Kingston are considered to have received support. For this reason, it is the recommendation of this report to harmonize both of the care and support indicators to be defined as any OVC or chronically ill person who has received any form of external support, rather than all forms of external support.

Table 10. External support for households with OVC

Per cent of OVC age 0–17 years living in households whose household received free basic external medical or school-related support in caring for the child in the 12 months before the survey or whose household received free basic external emotional, material or social support in caring for the child in the 3 months before the survey.

	Medical care (last 12 months)	Emotional /psychosocial support (last 3 months)	School-related assistance (last 12 months)	Social support (help in housework, legal support, etc) (last 3 months)	Material support (clothing, food, or financial support (last 3 months)	All types of support	Any type of support (at least one)	Number of children	
								Weighted	Unweighted
Blantyre									
Age									
0–4	3.6	3.6	na	0.0	0.0	0.0	3.6	11,401	33
5–9	10.9	13.3	30.4	0.0	0.0	0.0	19.8	18,045	49
10–11	7.8	5.6	27.8	5.6	5.1	0.0	13.4	11,364	31
12–14	6.6	10.4	22.6	2.3	1.7	0.0	16.1	14,327	43
15–17	6.2	8.1	6.4	1.1	0.0	0.0	13.5	16,230	48
Sex									
Male	4.7	9.7	20.0	2.5	0.0	0.0	14.0	33,477	94
Female	9.6	8.0	16.4	0.8	2.2	0.0	14.1	37,890	110
OVC composition									
OVC	7.3	8.8	18.1	1.6	1.2	0.0	14.0	71,367	204
Orphan	6.3	8.0	17.5	2.0	1.5	0.0	13.7	56,268	159
Vulnerable	8.8	16.9	21.2	2.3	0.9	0.0	21.3	28,563	82
Total	7.8	8.7	17.9	1.6	1.1	0.0	14.4	72,201	206
Kingston									
Age									
0–4	0.0	0.0	na	0.0	0.0	0.0	0.0	20,988	54
5–9	4.0	2.7	5.8	2.7	4.4	0.0	5.7	31,305	81
10–11	3.5	3.5	2.1	3.5	3.5	0.0	3.5	12,324	30
12–14	0.0	0.0	0.0	0.0	0.0	0.0	0.0	13,953	39
15–17	0.0	2.2	7.4	2.2	8.3	0.0	8.3	12,546	33
Sex									
Male	1.9	1.6	3.1	1.6	2.5	0.0	3.4	43,689	110
Female	1.8	1.8	3.5	1.8	3.7	0.0	3.7	47,428	127
OVC composition									
OVC	1.9	2.3	4.0	2.3	4.2	0.0	4.2	68,662	171
Orphan	0.0	1.3	6.1	1.3	1.3	0.0	1.3	20,133	54
Vulnerable	0.0	0.6	0.8	0.6	1.4	0.0	1.4	48,353	113
Non OVC	1.8	0.0	1.2	0.0	0.0	0.0	1.8	22,454	66
Total	1.8	1.7	3.3	1.7	3.1	0.0	3.6	91,117	237

'All types of support' does not include school related assistance for children ages 0–4. Children with missing data are excluded from this table.

Table 11. External support for households with chronically ill adults

Per cent of persons age 18–59 who are either chronically ill or who died within the last 12 months after being chronically ill whose households received free basic external medical support in the 12 months before the survey or whose household received free basic external emotional, material or social support in the 3 months before the survey.

	Medical care (within last 12 months)	Emotional or psychosocial support (within last 3 months)	Social support (help in housework, training of caregiver, legal services)	Material support (clothing, food, or financial support)	All forms of support	Any form of support (at least one)	Number of chronically ill or dead	
							Weighted	Unweighted
Blantyre								
Age								
18–29	35.4	15.7	0.0	13.7	0.0	60.9	4,243	14
30–39	47.7	48.8	10.7	24.9	10.7	63.0	5,224	15
40–49	52.1	27.7	10.3	10.3	10.3	69.5	2,399	7
50–59	14.9	25.6	17.8	0.0	0.0	43.4	2,347	7
Sex								
Male	42.7	27.3	3.5	9.4	3.5	55.7	7,093	22
Female	36.0	35.8	13.7	20.5	7.8	64.7	7,120	21
Status								
Chronically ill	42.2	29.6	9.0	13.5	5.1	63.3	10,858	33
Dead	30.2	37.7	7.4	19.8	7.4	50.2	3,355	10
Total	39.3	31.5	8.6	15.0	5.7	60.2	14,213	43
Kingston								
Age								
18–29	0.0	0.0	0.0	0.0	0.0	0.0	3,494	9
30–39	6.9	0.0	7.9	14.8	0.0	21.8	5,756	15
40–49	0.0	0.0	0.0	0.0	0.0	0.0	6,980	18
50–59	0.0	4.1	0.0	12.4	0.0	12.4	6,597	15
Sex								
Male	5.2	0.0	0.0	7.1	0.0	12.3	7,693	20
Female	0.0	1.8	3.0	7.4	0.0	7.4	15,135	37
Status								
Chronically ill	1.9	1.3	2.2	8.0	0.0	10.0	20,788	52
Dead	0.0	0.0	0.0	0.0	0.0	0.0	2,039	5
Total	1.8	1.2	2.0	7.3	0.0	9.1	22,828	57

One limitation that has been identified in the use of the external support indicator in household-based surveys, is that household-based samples of chronically ill people are not nationally representative because they exclude those who are hospitalized, institutionalized or homeless. As has been shown in the examples of Kingston and Blantyre, this is not the case with OVC; the number of institutionalized and homeless children is too small overall to affect national indicators. In this case, a household-based sample would in fact be nationally representative for all three sub-groups. However, this exercise did not determine the national representativeness of a household-based sample for chronically ill adults. The sample excluded adults who were hospitalized or institutionalized.

As previously mentioned, the definition of chronically ill (persons who have been sick for three of the past 12 months) is not an appropriate proxy for 'people who are sick with AIDS' in low-

HIV prevalence countries. This definition is likely to capture more adults sick due to other causes than due to AIDS.

Further analysis suggests, in a high-HIV prevalence setting such as Blantyre, 50–60 per cent of the adults classified as chronically ill can be expected to be sick because of AIDS. However, in Kingston, only 4 per cent of the adults classified as chronically ill can be expected to be sick because of AIDS (see box). The remaining chronically ill persons were likely sick from other causes, including cancer, diabetes or other chronic illnesses.

BLANTYRE, MALAWI:
- 802 adults in Household sample
- HIV prevalence = 20% (estimated urban)
- 802 x .2 = 160 HIV+ adults expected
- 160 / 9 = **18 adults with AIDS expected ***
- **33 sick adults found**

54 percent of chronically ill are AIDS-related

KINGSTON, JAMAICA:
- 1,065 adults in Household sample
- HIV prevalence = 2% (estimated urban)
- 1,065 x .02 = 21 HIV+ adults expected
- 21 / 9 = **2 adults with AIDS expected ***
- **52 sick adults found**

4 percent of chronically ill are AIDS-related

* Average life span post-HIV-infection is 9 years, with one year of illness. Therefore, approximately 1/9 of those who are HIV+ are expected to have AIDS.

For this reason, this report recommends that the data to calculate the indicator for care and support for chronically ill people only be collected in high-HIV prevalence countries (defined as a adult HIV prevalence of over five per cent). In countries with less than a five per cent prevalence rate, it is unlikely that the chronically ill people identified in the sample would be an appropriate proxy for 'people who are sick with AIDS.'

8. Discussion

In the pilot-testing phase of any new methodology, several issues are likely to arise that must be addressed if the methodology is to be replicated.

Intelligence gap

A major problem with the construction of the sampling frame for the street survey is what can be termed the 'intelligence gap.' In the case of Malawi, there was a lag time of over a month between the listing of the street locations and the fieldwork. With a population as fluid and mobile as homeless children, many changes could occur over this time. Children move from one place to another based on events that happen on a day-to-day and sometimes hour-to-hour basis (police harassment, blackouts, inclement weather, excessive noise, etc.). Information on where children slept even a week ago is potentially unreliable for accurate sampling purposes.

The PSUs, as defined, are therefore unstable because they are constantly changing in both the time and space dimensions. A PSU may contain 25 children today, 12 tomorrow and zero next week. The location of the PSU may shift from day to day or go out of existence altogether. New PSUs spring up regularly, depending on weather, security issues and other reasons.

Obtaining the measures of size was a very expensive operation in Blantyre because it entailed stationing interviewers at each PSU in the frame for the entire length of the time period associated with that PSU, just to make a rough count of the number of people on the street under age 18. Because of the time intensive nature of this methodology and the fluidity of the sites this stage of the sampling operation for homeless children was adjusted for Kingston and is not recommended in the revision of the sampling manual.

Thus, the idea of a representative sample of street locations may have to be abandoned for a less scientific but more practical means of finding homeless children, which would entail using a mobile team moving throughout the city based on information that was gathered at the time of the fieldwork. This would eliminate the 'intelligence gap and enable the interviewers the flexibility that the situation requires. This would be a more practical means of conducting a census of homeless children, rather than the above sample.

Night surveys

The Malawi survey took place largely at night; most time-location units were during the 8pm to 4am period. During the night it is too dark to see in the locations that people sleep. It is difficult to tell where people are sleeping and, if they are found, it is hard to determine a person's age.

Although the use of flashlights facilitated the night-based fieldwork somewhat, the interviewers were uncomfortable using them to shine lights on people's faces while they slept. They felt that it was both unethical and impractical to wake people up who are sleeping, from both a safety standpoint and from the perspective of bothering the very people who you need information from.

Weather is also an important consideration when looking at conducting street surveys. When it is cold or rainy, homeless children and adults alike often sleep in off-street locations. When it is warm, more people sleep outdoors. Either way, a weather-related bias exists when attempting to count homeless children, depending on what time of year the survey is conducted.

The hours selected for the survey fieldwork need to correspond to local activity patterns. It is impractical to schedule interviews during periods where there is unlikely to be a lot of activity (i.e. after 1 a.m. in Blantyre). The time periods must be determined in advance in collaboration with local experts, as periods of activity may differ in different cities within the same country.

Interviewing procedures were especially troublesome in Blantyre. There were elements of danger when interviewing late at night, problems of identifying sleeping persons as adults or children and reluctance to wake them up. Accordingly, the pilot test was modified in Kingston to avoid late-night interviews. In addition, sites were defined in Kingston as places where children congregate for their activities rather than where they sleep. Instead children were classified as homeless on the basis of where they slept the previous night, so it did not matter whether they were interviewed at an activity site or a sleep-site.

Implementation of the street survey

There are some complications that may make administration of the street survey difficult in nationwide settings. The hours of the street survey are currently very long (six-to-eight hour periods). As a general rule, it takes a very dedicated staff to remain at a location for such a long period in the evenings or at night. Social workers or people who work with street children may see the survey work as an extension of their jobs and a duty and/or a labour of love. Those working merely for a pay check, however, will be less willing to put the time and effort into the work. In this survey, all interviewers for the street component were trained professionals who work locally with homeless children. As such, they are more expensive, and more difficult to recruit than the typical household interviewer.

It is extremely important that the interviewers be trained professionals who are used to working with street children. In many cases, the interviewers will have already built a pre-existing rapport with the children. This level of trust makes the fieldwork much easier to conduct. However, one potential bias inherent in using social workers who have a previous relationship with the kids is that the interviewers already ‘know’ who the homeless children are and are therefore likely to overlook children who they either do not know or who they believe are not homeless. If trained social workers are unavailable, all potential interviewers must be carefully and thoroughly screened to assess their suitability to the task of interviewing homeless children. Even with dedicated survey staff, burnout and simple exhaustion is likely.

If national surveys are to be conducted, then it may be necessary to recruit local social workers who are familiar with the children in each area to conduct the fieldwork, rather than have a group of teams who travel to areas they are unfamiliar with to conduct surveys with children who they have not built up a previous rapport with. Interviewers must be very well trained and closely supervised. Since the number of individual interviews each interviewer will conduct is far fewer

than for the average household interviewer, they have a longer learning curve and may make basic mistakes for a longer period of time.

Inclusion of institutional and homeless OVC populations

As was shown in section 3, when calculating nationwide OVC care and support indicators, the proportion of children living outside of household settings (and therefore not included in a household-based sample) was small enough to be insignificant. As has been shown, the indicators do not change with the inclusion of either institutionalized or homeless children.

There were two primary goals for monitoring national OVC programmes; first, to measure the well-being of OVC through national indicators and, second, to measure the magnitude of the situation by estimating he number of OVC in a given population. This report concludes that for the calculation of national (or regional) indicators, it is not necessary to include institution or homeless children in the sample.

To estimate the number of OVC in a particular region, it is necessary to include both institution and homeless children in the sample frame. However, for the limited purpose of conducting a count of these children, it would not be necessary to interview these children using a questionnaire. The use of screening tools – the street roster and the institution roster – will be sufficient in collecting enough information to estimate the number of OVC.

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