# Measuring Outcomes among Children in Adverse Situations

## Indicators and Survey Tools

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MEASURE Evaluation

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## Indicators and Survey Tools

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The development of the Children in Adverse Situations Indicators and Survey Tools was a highly participatory process. The materials represent current best practices for the measurement of orphans and vulnerable children (OVC) and caregiver well-being in the context of OVC programs funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

The survey tools, indicator lists, and this manual were prepared by Jacqueline Hellen and Lisa Parker, at MEASURE Evaluation, Palladium, with support from Lisa Marie Albert (MEASURE Evaluation, Palladium) and Connor Goggin.

The tool development process was shepherded at the USAID by Sarah Dastur and Stephen Joshua Volle, with key input from the wider community of key population and OVC programs of PEPFAR and the Bill & Melinda Gates Foundation.

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# TABLES

# ABBREVIATIONS

| | |
|---|---|
| CP MERG | Child Protection Monitoring and Evaluation Reference Group |
| CDC | Centers for Disease Control and Prevention |
| CRC | Convention on the Rights of the Child |
| FSW | female sex worker |
| ILO | International Labour Organization |
| IRB | institutional review board |
| KP | key population |
| OVC | orphans and vulnerable children |
| PEPFAR | United States President's Emergency Plan for AIDS Relief |
| STI | sexually transmitted infection |
| USAID | United States Agency for International Development |
| USG | United States Government |
| WHO | World Health Organization |

# EXECUTIVE SUMMARY

Household surveys, such as the Demographic and Health Survey and the Multiple Indicator Cluster Survey, provide useful data on the vulnerabilities faced by children in the general population, but they often miss children who may be exposed to extreme adversity, such as children of female sex workers (FSWs), street children, and children working in mines. Globally, there are limited data on children living outside of traditional households, such as those living in the context of sex work or mining, or outside the care and protection of a primary caregiver, such as those living on the streets (Clay, et al., 2012). Service delivery organizations supporting these children also rarely share information and best practices in order to measure outcomes and performance.

Although research has shed some light on the vulnerabilities and needs of children living in such adverse situations, until now, no standardized indicators have been released to guide practitioners in measuring the extent of their risk to HIV. The goal of the Children in Adverse Situations Indicators and Survey Tools—available at https://www.measureevaluation.org/our-work/ovc/children-in-adverse-situations-indicators-and-survey-tools—is to answer the following question: "What improvements in well-being outcomes can be attributed to programs supporting children of FSWs, street children, and children working in mines?" The indicators and tools were specifically developed to expand the evidence base required by child welfare systems and programs in low- and middle-income countries to systematically reduce the vulnerability of these specific populations.

The Children in Adverse Situations Indicators and Survey Tools help countries or organizations assess and strengthen their information base on well-being outcomes of children in these populations. This suite consists of a holistic set of standardized outcome indicators and corresponding survey tools that have been deemed essential to ensuring more effective sharing of outcome data both in and between countries and programs and to expanding the evidence base of these invisible children to better understand their needs.

# INTRODUCTION

In 2013, MEASURE Evaluation, which is funded by the United States Agency for International Development (USAID) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), released the Child, Caregiver, and Household Well-Being Survey Indicators and Tools for Orphans and Vulnerable Children (OVC) Programs. The indicators and tools were developed to help OVC programs collect information on their household-based child and caregiver beneficiaries to better understand their needs and ultimately respond to improve beneficiary outcomes. They are intended for use in family household units (Chapman, Foreit, Hickmann, & Parker, 2015). However, there are several international programs that support children outside of "traditional" household units, such as children working in mines, children living on the street, and children of FSWs. These programs require information on outcomes specific to child populations facing extreme adversity to provide more specialized support.

MEASURE Evaluation developed a suite of survey tools, standardized outcome indicators, and this implementation manual to guide programs supporting children in adverse situations to effectively measure the impact of their interventions on well-being outcomes. The tools, indicator lists, and this manual fill an important measurement gap that will allow programs serving these children to better understand their target populations and to evaluate their programs effectively to inform evidence-based service delivery and, ultimately, ensure that child well-being is improved. These materials were also developed to support Objective Five of the United States Government Action Plan on Children in Adversity, which is to increase the number of outcome and impact evaluations on interventions to assist children outside of family care or minimize exposure to violence, exploitation, abuse, and neglect that can be generalized to the larger target group (Boothby, 2017).

The Children in Adverse Situations Indicators and Survey Tools serve the following purposes:

- Enable and standardize the production of program-level well-being data on children of FSWs, street children, and children working in mines
- Produce actionable data to inform programs and enable course corrections for programs targeting these children
- Enable comparative assessments of child well-being across projects and geographical regions

# BACKGROUND ON THESE POPULATIONS

## Children in Adverse Situations

Many children in the world live in conditions or environments of serious deprivation or danger, increasing their vulnerability to profound life cycle risks that have an impact on their development (United States Department of State, et al., 2012). Adverse childhood experiences, or any type of abuse, neglect, or other traumatic experience that occurs to people under the age of 18, have been linked to risky health behaviors, chronic health conditions, low life potential, and early death (Centers for Disease Control and Prevention [CDC], 2019). The more adverse childhood experiences that a child experiences, the higher the likelihood that he or she will experience negative health outcomes (CDC, 2019).

For the purposes of this manual and the survey tools, children in adverse situations are defined as children living in the context of individual, social, and programmatic vulnerability (Silva, Chiesa, Verissimo, & Mazza, 2013). These children may include children outside of family care, defined as "children living without at least one parent and without an adult, kin or otherwise, who is fulfilling parental roles and is permanently engaged in the child's lifelong wellbeing" (Stark, Rubenstein, Muldoon, & Roberts, 2014, p. 3), or children in family care who are residing in contexts where they are regularly exposed to extreme adversity and vulnerability to HIV. Children outside of family care can include children living or working on the street, institutionalized children, trafficked children, children affected by conflict and disaster, and children who are exploited for their labor, such as those working in mines (Boothby, et al., 2012). Children in adverse situations may also be children living in family care, including children of FSWs, street children, and children working in mines residing with a caregiver.

### FSW Caregivers and Their Children

Evidence suggests that most FSWs become mothers, ranging from 69 percent in Côte d'Ivoire to 93 percent in Mexico. Maternal morbidity and mortality among FSWs and the health and well-being of their children have been identified as two critical human rights crises that have been neglected on the international stage. FSWs have a disproportionate risk of maternal mortality given their high rates of HIV, unintended pregnancy, stillbirth, and abortion, and especially among FSWs in sub-Saharan Africa. When they become pregnant, their pimps often force them to continue to work until they deliver and prevent them from accessing antenatal care. They are also often exposed to stigma at health facilities and to violence (Willis, Welch, & Onda, 2016).

Children of FSWs are at serious risk for HIV, congenital syphilis, fetal alcohol syndrome, physical and sexual violence, and tuberculosis (Willis, et al., 2016). Other serious health problems have also been reported, including neonatal deaths, low birthweight, prematurity, birth defects, and neonatal abstinence syndrome. These children face cognitive developmental delays, neglect and deprivation, separation from parents, difficulties accessing health care or education, and social marginalization (Beard, et al., 2010). They are often groomed or forced to enter the trade; daughters will work as maids until they are forced into sex work and boys are trafficked into various forms of child labor. They often experience psychological issues, and many engage in criminal behavior and take drugs (Willis, Hodgson, & Lovich, 2013).

## Street Children

Street children are defined as "any girl or boy who has not reached adulthood, for whom the street (in the broadest sense of the word, including unoccupied dwellings, wasteland, etc.) has become his or her habitual abode and/or source of livelihood, and who is inadequately protected, supervised or directed by responsible adults" (Robinson & Branchini, 2015). UNICEF defines street children as "children at risk," "children on the street," "children of the street," and "abandoned children": those who live with families but work on the streets to supplement the family income, those who have some family support but work on the streets, those who live and work on the streets without any family support, and those who live completely on their own, respectively (Mounir, Attia, & Tayel, 2007). Children of the streets tend to see the streets as their home, where they have a sense of belonging and even family among companions. It has been shown that children often turn to the streets for a variety of reasons, including family history of drug abuse, family violence, low self-esteem, depression, and lower family income level or poverty (Mathur, Rathore, & Mathur, 2009). Once children resort to the streets, they may be exposed to harassment and abuse from the police, accusations of petty crimes (Mounir, et al., 2007), and physical, psychological, and sexual abuse. A pilot study in India conducted among 200 street children in 2009 determined that overall abuse was reported by 61.8 percent of the children, and of those, 61.5 percent reported moderate abuse, 16.9 percent reported severe abuse, and 19.7 percent reported very severe abuse, respectively (Mathur, et al., 2009). The children in this study were most often exposed to verbal and psychological abuse. There have also been reports that sex exchange, sex work, and drug use are common practices among street children, often used as coping mechanisms, and making these children especially vulnerable to HIV/AIDS (Towe, ul Hasan, Zafar, & Sherman, 2009).

## Children Working in Mines

In 2016, it was estimated that 9 percent (152 million children) of the world's population of children were involved in child labor. Of these, 4.6 percent (73 million children) were involved in some form of hazardous work (International Labour Organization [ILO], 2017). The ILO Convention No. 182 states that all children under the age of 18 must be protected from working in mines because it is among the worst forms of child labor owing to the health risks to children (ILO, 2008). These children are exposed to dust and other minerals, explosives, mercury, cyanide, and other chemicals, and to accidents and falling rubble. There is little research or evidence available on children working in mines given the often illegal, informal, and remote operations of mines and quarries around the world. Most miners come from villages located near to mines or quarries, and they typically engage in work with their families; children come to work and play in the mines while their caregivers work. Settlements predominantly include single male migrants who contribute to high levels of sexual exploitation of children. Children working in mines generally work there because of poverty, lack of alternative work or schooling options, or to pay for their own schooling, among other reasons. Despite national labor laws, children continue to engage in mining because the laws are often not enforced in the remote regions of the world where these mining communities usually exist (Thorsen, 2012).

# AUDIENCE

## Programs Serving Children in Adverse Situations

The Children in Adverse Situations Indicators and Survey Tools are primarily designed for outcome monitoring and evaluation at the program level. The indicators and tools can be used by ministries, national child welfare and protection programs, and governing bodies or authorities, and by nongovernmental organizations seeking to inform program planning and to assess the progress and effectiveness of program implementation. The indicators and tools should be adapted to the sociocultural context. Although the indicators and tools can be implemented by programs for internal outcome monitoring, the outcome evaluation process should be led by a person or an organization external to program implementation. The evaluation process should include stakeholders from across the child welfare system and the health system at various levels of the system.

## Programs Serving Female Sex Workers and Their Children

The USAID Strategy for Addressing Children of Key Populations (KPs) asserts that although children of KPs face tremendous levels of risk and vulnerability in care, development, and protection (contributing to an elevated risk for HIV/AIDS), they are largely ignored by HIV/AIDS agendas for KPs. USAID has called for OVC, KPs, and prevention of mother-to-child transmission/pediatrics programs to address the priority needs of children, parents, and families as an entire family unit, and to strengthen both the adult and pediatric continuum of care to meet 95-95-95 goals (USAID, 2017).

There are existing examples of PEPFAR-supported programs in Cameroon, India, and Tanzania working together to offer service packages for FSW caregivers and their children, where KP and OVC program partners are attempting to integrate care to address family needs holistically. The questionnaires and indicator list for children of FSWs can be used by KP and OVC programs alike, because they aim to evaluate the impact of integrated services and interventions on FSW caregivers and their children as one family unit.

## Programs Serving Street Children and Children Working in Mines

Other populations supported by United States Government (USG) funding around the world have included separated children, such as children in residential care facilities; children working or living on the street; children migrating for work; vulnerable adolescent girls; young domestic workers; foster children; trafficked children; child laborers; children in alternative care; children working in mines; and children in armed conflict. MEASURE Evaluation decided to focus on the need for an expanded evidence base among programs supporting street children and children working in mines because they are the primary populations served by the USG, in addition to children of FSWs.

# SURVEY TOOL DEVELOPMENT

MEASURE Evaluation took the following steps to develop the survey indicators and tools for evaluating outcomes of children in adverse situations:

1. We conducted a literature review by using keywords in PubMed and other online databases to better understand the current global best practices in measuring outcomes for street children, children working in mines, FSW caregivers, and children of FSWs.

2. We performed semi-structured telephone interviews with key stakeholders in international donor agencies, service delivery organizations, and with other subject area experts who were identified through the literature review, USAID support, and by referral. These interviews were used to identify existing indicators and documentation/literature; understand best practices and strengths and weaknesses in outcome evaluation; examine cooperation between partners supporting children in adverse situations to measure outcomes and performance; and better understand the challenges in data collection, analysis, and use of data for these populations. We also obtained information about possible new indicators that would be helpful to implementing partners and donor agencies.

3. We developed two large compendiums of indicators sourced from the literature, documentation received from key informants, and performance monitoring plans from programs serving children in adverse situations.

4. We established two consolidated lists of the most commonly used subdomains and data elements from the literature review and performance monitoring plans for (1) children of FSWs and (2) street children and children working in mines, respectively.

5. We refined and reduced the number of subdomains and data elements after soliciting feedback from key informants.

6. We transformed the data elements and subdomains into corresponding outcome indicators for each group.

7. We created data collection tools using measures sourced from validated and internationally recognized questionnaires of a similar nature, such as the CDC's Violence Against Children Surveys, ICAP's Population-Based HIV Impact Assessment, the Integrated HIV Biobehavioral Surveillance Toolbox, and others, to measure the outcome indicators selected.

# DESCRIPTION OF THE INDICATORS AND SURVEY TOOLS

The Children in Adverse Situations Indicators and Survey Tools are listed below and described in this manual:

## Indicator Lists

- Children of Female Sex Workers Outcome Indicator List
- Street Children and Children Working in Mines Outcome Indicator List

## Survey Tools

### Questionnaires for Children of Female Sex Workers

- Questionnaire for Adolescent Children (Ages 10–17) of Female Sex Workers (available in Word)
- Questionnaire for Children (Ages 0–9) of Female Sex Workers (available in Word)
- Questionnaire for Female Sex Worker Caregivers, Ages 18 and Older (available in Word)

### Questionnaires for Street Children and Children Working in Mines

- Questionnaire for Adolescent Street Children and Adolescent Children Working in Mines (Ages 14 to 17) (available in Word)
- Questionnaire for Street Children and Children Working in Mines (Ages 0 to 13) (available in Word)

Table 1 presents a comparison of the outcome measures included in the children of FSWs questionnaires versus those included in the questionnaires for street children and children working in mines. We organized the indicators and corresponding measures across the PEPFAR domains of eligible OVC services: healthy, stable, safe, and schooled. Sources for these outcome measures can be found in the indicator lists.

**Table 1. Children in adverse situations outcome measures**

| Outcome Measures | Questionnaires for Street Children and Children Working in Mines | | | | Questionnaires for Children of FSWs | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Age groups | All children ages <18 | Children ages <5 | Children ages 5–17 | Children ages 14–17 | Caregiver (ages 18+) | All children ages <18 | Children ages <5 | Children ages 5–17 | Children ages 10–17 |
| **HEALTHY** | | | | | | | | | |
| **HIV/sexually transmitted infection (STI) prevention, status, and treatment** | | | | | | | | | |
| Comprehensive knowledge about HIV/AIDS | | | | | X | | | | |
| HIV status | X | | | | X | X | | | |
| HIV testing and received results | X | | | | X | X | | | |
| Early infant diagnosis | | X | | | | | X | | |
| Currently on antiretroviral therapy | X | | | | X | X | | | |
| Antiretroviral therapy adherence | X | | | | X | X | | | |
| Retention in HIV care | X | | | | X | X | | | |
| Self-report of suppressed viral load | | | | | X | | | | |
| Shows signs and symptoms of STIs | | | | X | X | | | | X |
| STI screening | | | | X | X | | | | |
| STI treatment | | | | X | X | | | | |
| Pre-exposure prophylaxis | | | | | X | | | | |
| **Sexual behavior and reproductive health** | | | | | | | | | |
| Ever sex | | | | X | | | | | X |
| Age at sexual debut | | | | X | | | | | X |
| Forced sex at first sex | | | | X | | | | | X |
| Mean number of sexual encounters in the past 12 months | | | | X | | | | | X |
| Transactional sex in the past six months | | | | X | | | | | X |
| Pregnancy | | | | X | | | | | X |
| Mean number of sexual encounters per week | | | | | X | | | | |

| Outcome Measures | Questionnaires for Street Children and Children Working in Mines | | | | Questionnaires for Children of FSWs | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Age groups** | **All children ages <18** | **Children ages <5** | **Children ages 5–17** | **Children ages 14–17** | **Caregiver (ages 18+)** | **All children ages <18** | **Children ages <5** | **Children ages 5–17** | **Children ages 10–17** |
| Condom use at last sex | | | | X | X | | | | X |
| Consistent condom use in the past week during sexual intercourse with any kind of partner | | | | | X | | | | |
| **Drug or alcohol use** | | | | | | | | | |
| Current use of drugs or alcohol | | | X | | X | | | | X |
| Current intravenous drug use | | | | X | | | | | X |
| Alcohol/drug dependence | | | X | | | | | | X |
| **OVC program services** | | | | | | | | | |
| Services accessed or received in the past three months | X | | | | X | X | | | |
| **Depression** | | | | | | | | | |
| Depressive symptoms | | | | | X | | | | |
| **Child mental well-being** | | | | | | | | | |
| Emotional and behavioral difficulties (ages 2+) | X | | | | | X | | | |
| **STABLE** | | | | | | | | | |
| **Living situation** | | | | | | | | | |
| Living outside of family care | X | | | | | | | | |
| Living with family members | X | | | | | | | | |
| Living with an unrelated adult who provides consistent care | X | | | | | | | | |
| **Social support** | | | | | | | | | |
| Someone to turn to for suggestions about how to deal with a personal problem | | | | X | | | | | X |
| Someone to show them love and affection | | | | X | | | | | X |

| Outcome Measures | Questionnaires for Street Children and Children Working in Mines | | | | Questionnaires for Children of FSWs | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Age groups | All children ages <18 | Children ages <5 | Children ages 5–17 | Children ages 14–17 | Caregiver (ages 18+) | All children ages <18 | Children ages <5 | Children ages 5–17 | Children ages 10–17 |
| Regular contact with a social worker, community volunteer, or other kind of community worker | X | | | | | X | | | |
| **Caregiver-child relationship** | | | | | | | | | |
| Positive parental involvement and monitoring and supervision | | | | X | | | | | X |
| **Food security** | | | | | | | | | |
| Food insecurity | X | | | | X | X | | | |
| **Economic stability** | | | | | | | | | |
| Contractual arrangement | | | | | X | | | | |
| Ability to pay school fees and medical costs in the past year | | | | | X | | | | |
| Supplemental income to sex work | | | | | X | | | | |
| Self-reported savings in the past year | | | | | X | | | | |
| **Birth certificate** | | | | | | | | | |
| Birth certificate | X | | | | | X | | | |
| **SAFE** | | | | | | | | | |
| **Childcare** | | | | | | | | | |
| Inadequate adult care (ages <10) | | X | X | | | | X | X | |
| **Child labor** | | | | | | | | | |
| Child labor and chores | | | X | | | | | X | |
| Earn money for family | | | X | | | | | X | |
| Work/chores interfere with school or sleep | | | X | | | | | X | |
| **Violence** | | | | | | | | | |
| Witnessing physical violence | | | X | | | | | | |

| Outcome Measures | Questionnaires for Street Children and Children Working in Mines | | | | Questionnaires for Children of FSWs | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Age groups | All children ages <18 | Children ages <5 | Children ages 5–17 | Children ages 14–17 | Caregiver (ages 18+) | All children ages <18 | Children ages <5 | Children ages 5–17 | Children ages 10–17 |
| Witnessing physical violence of mother/caregiver | | | | | | | | | X |
| Emotional violence | | | X | | | | | | X |
| Physical violence | | | X | | | | | | X |
| Sexual abuse | | | X | | | | | | X |
| Sexual assault or rape | | | | X | | | | | X |
| Receipt of post-violence help | | | X | | | | | | X |
| Post-violence post-exposure prophylaxis uptake | | | X | | | | | | X |
| **SCHOOLED** | | | | | | | | | |
| **Education** | | | | | | | | | |
| Early childhood education (ages 3–4) | | X | | | | | X | | |
| School attendance | | | X | | | | | X | |
| School progression | | | X | | | | | X | |
| School enrollment | | | X | | | | | X | |

# IMPLEMENTING THE SURVEY TOOLS

## Defining Participants

### Survey Tools for Children of Female Sex Workers

The first set of tools should be administered to FSWs and their children who are program beneficiaries.

The **Questionnaire for Female Sex Worker Caregivers** is administered to any female sex worker,[1] ages 18 and older, who has at least one biological or adopted child, or at least one child who she looks after on an ongoing or indefinite basis. She should be permanently engaged in this child's lifelong well-being. Only FSWs who are residing with their child(ren) are eligible for participation in the survey.[2]

The **Questionnaire for Children of Female Sex Workers** concerns children ages 0 to 9, whether biological, adopted, or in the permanent care of an FSW and currently residing in her same locale.[3] This questionnaire is administered to an FSW caregiver about her child(ren).

The **Questionnaire for Adolescent Children of Female Sex Workers** is administered to any adolescent of an FSW, ages 10 to 17, whether biological, adopted, or in the FSW's permanent care and currently residing in her same locale.

### Survey Tools for Street Children and Children Working in Mines

The second set of tools should be administered to street children and children working in mines. For the purpose of these survey tools, children living and/or working on the street are defined as children ages 0 to 17 who permanently live and sleep on the street or engage in work for survival on the street with no responsible adult.

The **Questionnaire for Adolescent Street Children, and Adolescent Children Working in Mines (Ages 14 to 17)** is administered to the *person most knowledgeable about* the child beneficiary regarding any child, ages 0 to 13. The person most knowledgeable about the child's life and circumstances is someone who knows the child participating in the study well. These people can include involved older siblings, teachers, youth care workers, and others who play a significant role in the child's life and are familiar with his/her challenges, opportunities, and resources (Ungar, 2016). Adolescents ages 12 and 13 have been included in our definition of a "child," given the ethical issues of obtaining informed consent from "adolescents" below the age of 14 without

[1] FSWs include "female adults (18 years of age and above) who receive money or goods in exchange for sexual services, either regularly or occasionally. Sex work is defined as consensual sex between adults, and can take many forms, and varies between and within countries and communities. Sex work also varies in the degree to which it is more or less 'formal' or organized" (World Health Organization [WHO], 2012). "As defined in the Convention on the Rights of the Child (CRC), children and adolescents under the age of 18 who exchange sex for money, goods or favors are 'sexually exploited' and not defined as sex workers" (WHO, 2016, p. 12).

[2] Any FSW who has a living child who most frequently sleeps in a locale away from her is not eligible for inclusion. This would include any children who live with family or community members or in a residential care facility, hostel, boarding school, or alternative care facility away from the locale where the FSW most frequently sleeps. Although many FSWs decide to send their children away to live in an alternative residence to prevent their exposure to abuse, exploitation, violence, and neglect, others continue residing with their children even in brothels or where they continue to service clients (Pardeshi & Bhattacharya, 2006, p. xiii).

[3] This locale may include impermanent or permanent living situations. Locations of residence may include the street or public spaces, rented accommodation, shelter, brothel, hostel, hotel, own home, relative's home, or other (Willis, et al., 2014).

parental consent (because many of these adolescents are living without a formal guardian) (Stark, et al., 2014). The child questionnaire can be administered to an older sibling ages 14 or older, about their siblings younger than age 14, if they are the only most knowledgeable person available. (See the Consent Process section below for more details.)

The **Questionnaire for Street Children and Children Working in Mines (Ages 0–13)** is administered directly to adolescents ages 14 to 17.

## Procedures for Data Collection

The collection of these data requires a documented protocol, outlining a technically robust survey design. An experienced and qualified team should develop the protocol and involve a statistician to support the sampling of the population(s) (Stark, et al., 2014). The protocol, including the questionnaires, should undergo ethical review in the country of study and approvals should be received before the survey begins (WHO, 2018). FSW caregivers and other caregivers or people most knowledgeable about street children and children working in mines should be actively engaged throughout the study design and development phases through various formal and informal discussions.

### Adapting and Translating the Tools

Investigators should adapt the tools to fit their study objectives and adjust the question language to align with local discourse and to enhance clarity. Recall periods should not be changed. In many cases, the tools will need to be translated. During translation, it is important to agree on a variation that maintains the core integrity of the question and to not translate verbatim. During adaptation and translation, the goal is always to maintain the integrity of the indicators. All sections of the questionnaires are not required. Programs providing services impacting a specific set of indicators can select those sections that are appropriate. Scales detailed in the indicator lists should be reviewed to ensure that the integrity of the scale is not compromised by picking and choosing questions.

The tools—including all translated survey questions and response categories—should be pilot tested and further refined to ensure that they produce valid data in the country and context of the survey (Stark, et al., 2014). Most questions in the Children in Adverse Situations Indicators and Survey Tools were sourced from validated questionnaires that have been conducted in developing country contexts. However, these tools have not been piloted in their entirety in any context. Survey teams should be prepared to be responsive to community feedback and to make changes to the survey protocol. For example, there is potentially the need to expand the age ranges or geographic spread of the questionnaires, or adjust the wording, to stay in line with the realities on the ground given pre-test results. Contextualization is vital to ensure the success of survey implementation.

### Enumerators

The tools should ideally be administered by trained data collectors who are external to the provision and delivery of services or to the program. The size of the survey team should correlate with the size of the geographic area and travel required to reach all data collection sites. The team should be provided with specialized training focused on confidentiality and data security procedures to protect the identifiable information obtained, and context-specific understanding of street, sex worker, and mining culture (Stark, et

al., 2014). Members of the data collection team should be trained in the principles of research ethics and should be required to read and sign a confidentiality agreement. All should pass a child protection screening and should be trained in disclosure and distress protocols. (See the Child Rights and Protection Procedures section below for more details.)

Data collectors should be fluent in the primary language spoken in the areas where respondents reside because the contextualization of phrasing is key. A diverse set of enumerators (ethnicity, sexual orientation, faith), with professional competency to work with children, such as licensed social workers, should be employed to correspond to the diverse profiles of the children and adults to be interviewed (Nyamukapa, et al., 2010).

## Ethical Considerations

The data collection tools cannot be administered to any child, caregiver, or person most knowledgeable without written ethics approval from a research ethics committee or institutional review board (IRB). Approval should be obtained before the pilot phase of tool administration. The IRB or ethics committee should review the protocol, tools, and consent/assent forms for consideration in its decision. Relevant ministries, such as ministries of health and social development, whose mandate is to protect and support these target populations should also provide written approval before data collection and should be involved in the survey design and its implementation.

Informed consent and assent should be received before the administration of any questionnaire. Respondents have a right to share and receive information and a right to privacy. The enumerators should avoid pressuring participants to respond to the questions. Researchers should be wary of desirability bias because there may be pressure on respondents that makes them feel the need to respond positively. The FSW caregiver and person most knowledgeable should be interviewed out of earshot of others, including the child and/or adolescent in question. Children should be interviewed out of earshot but in plain sight of their caregiver or the person most knowledgeable. All information obtained from the interviews should be kept confidential (Chapman, et al., 2015).

### Consent Process

In many settings, adults are defined as people ages 18 or above who have the legal capacity to make decisions on their own about whether to participate in research. The United Nations Convention on the Rights of the Child (CRC) defines children as people below the age of 18 years and adolescents as people ages 10 to 17 years (WHO, 2018).

Any person below the age of 18 is not legally capable of providing consent to participate in research autonomously, nor does she or he have the ability to make an independent decision. Autonomous participation in research should consider age of maturity and mental competence (WHO, 2018).

During the interviews with adolescents, the enumerators should receive informed consent from the caregiver or person most knowledgeable, as applicable or available, and assent from the adolescent to be interviewed. Assent is defined as the "willingness to participate in research, evaluations or data collection by persons who are by legal definition too young to give informed consent according to prevailing local law but who are old enough to understand the proposed research in general, its expected risk and possible benefits, and the activities expected of them as subjects" (WHO, 2018, p. 14). Assent procedures "must take into account not

only the age of children, but also their individual circumstances, life experiences, emotional and psychological maturity, intellectual capabilities and the child's or adolescent's family situation" (WHO, 2018, p. 15). Participants below the age of 18 should be extensively involved in the decision-making process as is appropriate for their age and capacity (WHO, 2018).

During the administration of the questionnaires for street children and children working in mines, the enumerators may run into child and adolescent beneficiaries who do not have a person most knowledgeable or a caregiver of any kind.[4] In this event, children ages 0 to 13 should not be interviewed under any circumstances. However, children ages 14 to 17 can be interviewed if the child is deemed to be mature enough to participate in the research and, therefore, able to consent autonomously. Enumerators can seek a waiver of parental consent from the IRB Research Ethics Committee if the person most knowledgeable or the caregiver of the child cannot be located, or if the child wishes to participate without the knowledge of the caregiver or person most knowledgeable. The survey team should adapt the age ranges for the questionnaires for street children and children working in mines based on local laws around consent for emancipated minors (WHO, 2018).

Children should be given the opportunity to determine their interest in being involved in research or a decision that involves them, per Article 12 of the CRC,[5] and thus enumerators should give weight to a child's views on his or her participation in the research if she or he demonstrates decision-making capacity.[6] Consent or assent can be withdrawn by participants at any time (WHO, 2018). Moreover, parental/guardian consent does not mean that the adolescent will participate. The adolescent should give assent and his or her decision to withhold assent carries more weight than consent of the caregiver or person most knowledgeable.

If a respondent is illiterate, the enumerator should read the consent form aloud. Each respondent should be provided with adequate time to ask questions at any point during survey administration. If the respondent agrees, she or he should provide either a signature, a mark, or oral consent per the study protocol. Participation should be informed and voluntary. The protocol should detail any potential direct or indirect risks to participants. Information should remain confidential and should be reported only in aggregate form. Prior to questionnaire administration, enumerators should provide participants with a written summary of the survey and its purpose (and other information about the time involved), an assessment of the risks and benefits of participation, and a point of contact to provide information about the survey and to receive any follow-up questions (WHO, 2018).

## Child Rights and Protection Procedures

Investigators should ensure that no harm is brought to the participants during or as a result of data collection, compilation, or use. Investigators should determine any potential harm that participants may endure because of participation in the survey and work to minimize or eliminate it. A child protection policy and code of conduct

[4] This does not apply to the questionnaires for children of FSWs because these tools should not be administered unless the adolescent/child is living with his/her FSW caregiver.

[5] Article 12 of the CRC designates that "children shall be assured the right to express their views freely in all matters affecting them, their views being given due weight in accordance with the child's age, level of maturity, and what is in their best interest" (WHO, 2018).

[6] Capacity: the enumerator should ensure that the person most knowledgeable can make decisions to give permission for the child to participate in the research. Capacity is defined as the "ability to understand material information, appreciate the situation and its consequences, consider the treatment options, and communicate a choice" (WHO, 2018, p. 12).

for researchers should be developed to ensure that staff do not engage in any behavior that may be negatively construed or potentially abusive (Child Protection Monitoring and Evaluation Reference Group [CP MERG], 2012) (for example, Laws & Mann, 2004). This should include guidance for screening data collectors, training data collectors in child protection, fieldwork monitoring and supervision, ongoing support for team members, and establishing a child protection response system. The child protection policy should be aligned to a code of conduct, which is then signed by all members of the survey team (Chapman, et al., 2015). The safety of respondents and enumerators is paramount. Enumerators should be trained on a specific protocol and policy for referral that has been prepared before data collection starts so that it is very clear how enumerators should refer respondents to relevant services in the event that respondents request assistance or reveal themselves to be at risk of harm or currently experiencing violence.

The privacy of respondents should be protected, and privacy rights should be discussed during the consent process. The principle of confidentiality should be appropriately balanced with the need to act to provide immediate protection to the child, when necessary. Enumerators should evaluate whether acting will expose the child to increased risk. Such factors as the child's demographics, physical and emotional security and development, disability, illness, and the need to protect the child from any physical or psychological harm are important considerations when determining the best interests of the child. Respondents should be made aware of this exception to maintaining confidentiality during the consent/assent process. The survey team should be trained on local reporting laws and procedures and have a plan for mandatory reporting requirements (WHO, 2016).

## Violence

Survey teams should consider ethical and safety recommendations for research on violence. (See *Putting Women First: Ethical and Safety Recommendations for Research on Domestic Violence Against Women*, Garcia-Moreno, Watts, Heise, & Ellsberg, 2001; *Ethical and Safety Recommendations for Intervention Research on Violence Against Women*, WHO, 2016; *Guidance on Ethical Considerations in Planning and Reviewing Research Studies on Sexual and Reproductive Health in Adolescents*, WHO, 2018; and *Ethical Principles, Dilemmas, and Risks in Collecting Data on Violence Against Children*, CP MERG, 2012.)

The collection of information, especially about violence and sexual behavior, should be handled with extreme caution and care because the recounting of experiences can lead to trauma and embarrassment. This includes consideration during data storage and protection of personally identifiable information of respondents (CP MERG, 2012). Questions about violence should only be administered in a private setting, with the respondent alone, at his or her convenience, out of earshot but in plain sight of their caregiver or the person most knowledgeable (unless a waiver is obtained). Studies should be framed in the context of women and children's health, life experiences, or family relations, instead of violence alone. Only one person per family unit should be asked questions about violence. Therefore, an enumerator cannot administer the violence section from the survey tools for street children and children working in mines to both the adolescent and the child if they are from the same family unit. In that same vein, questions about violence sourced from the survey tools for children of FSW or otherwise cannot be administered to both the FSW caregiver and her adolescent. Prior to data collection on violence, survey teams should also consider how data from data collection on violence will be used and whether programs have the capacity or wherewithal to support people if experiences of violence are disclosed (WHO, 2016).

# DATA ANALYSIS AND USE

Data from these survey tools can be used to inform strategic planning and resource allocation decisions, for program planning/design and program management, and to advocate for resources for children of FSWs, street children, and children working in mines and their families. These survey indicators and tools were primarily developed for outcome evaluation. Indicators were selected that are amenable to change over time across a wide range of program settings. Some outcome indicators may take a long time to manifest and may rely on referrals to other OVC, KPs, prevention of mother-to-child transmission, or pediatrics programs. In addition to program outcome indicators, there are a limited number of indicators that programs may not be able to change but which may provide important demographic or contextual information that can help with the interpretation of the findings.

Although baseline and end line data can be compared to determine the effect of participation in program interventions on beneficiary well-being, the extent to which any change in well-being (whether it is positive or negative) can be attributed to a particular intervention or program is not assured. The ability to attribute changes in well-being to program impact improves if investigators gather information from a comparison group at the same two points in time (Chapman, et al., 2015). Whenever possible, the results should be triangulated with data already being collected on a regular basis by case workers during case management. Moreover, qualitative data can be been used to enrich outcome results and should be used to evoke the perspectives of children from these populations, given the complexity of their adversity.

It is important for programs to engage with other stakeholders involved in supporting these populations at national and community levels to ensure that outcome results are shared and used across the continuum of care. Although funding mechanisms between programs supporting these children and their caregivers may diverge, information sharing between programs is essential. A data for action workshop is recommended, per the CDC Violence against Children Survey standard, to directly respond to results and to develop a response plan to improve the quality of life of vulnerable children and their families.

# CONCLUSION

Children in adverse situations are often not directly supported by HIV/AIDS programming, because households are the easiest and most frequently used entry point for programs supporting orphans and vulnerable children. To our knowledge, no other tools of this nature are available for comprehensive well-being outcome measurement among at-risk populations of children and their caregivers living outside of traditional households. These tools and indicators can be applied in several contexts to any type of program supporting these populations to advance wellbeing outcomes across the healthy, safe, schooled, and/or stable intervention areas.

Programs supporting these children experience challenges in collecting well-being outcomes among these populations given their mobile and transitory nature, and the many sensitivities in accessing these populations. We hope that these tools and indicators are a step in the right direction for improving our ability to adequately comprehend the full spectrum of needs among these vulnerable and at-risk children and their families living in adverse situations.

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# APPENDIX A. STAKEHOLDER CONSULTATIONS

Key stakeholders crucial to this endeavor were interviewed from the following organizations:

- Columbia University
- Consortium for Street Children
- Tulane University
- London School of Hygiene and Tropical Medicine
- John's Hopkins University Bloomberg School of Public Health
- Maestral International
- Retrak
- PACT
- FHI 360, LINKAGES Project, Cote d'Ivoire and India
- University of California, Los Angeles
- Karnataka Health Promotion Trust, India
- Care's Continuum of Prevention, Care and Treatment of HIV/Aids with Most-at risk Populations in Cameroon (CHAMP) Project, Cameroon
- A Family for Every Child
- International Justice Mission
- Duke University Global Health Institute
- Harvard University Chan School of Public Health
- REVE Project, Cote d'Ivoire, implemented by the International Rescue Committee, Jhpiego, Futures Group, and Save the Children
- Jhpiego, SAUTI Project, Tanzania
- The Bill & Melinda Gates Foundation, Avahan Project, India
- Caris Foundation International, BEST Project, Haiti
- Displaced Children Orphan Fund (DCOF)
- USAID
- UNICEF
- Catholic Relief Services headquarters and KIDSS Project, Cameroon

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