SMALL ALSO HAVE SOMETHING TO SAY...

A report on research into the effects of HIV/AIDS on children in six Asian countries

February 2006

Save the Children

Cover Photo: Children’s discussion group, Cambodia

CONTENTS

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"Small also have something to say..." tries to reflect the views of children on HIV/AIDS and how the epidemic affects them. Save the Children would like to thank the many children who participated in this research, especially those whose words are quoted in this report.

The material in the report is drawn from country research reports and discussions with Save the Children researchers in Cambodia, China, Indonesia, Lao PDR, Myanmar and Thailand.

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This report was written by Lindsay Daines and edited by Elaine Ireland.

The research project on which this report is based was developed and coordinated by Elaine Ireland.

ACRONYMS AND DEFINITIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral therapy
DFID	Department for International Development
HIV	Human Immuno-deficiency Virus
IDU	Injecting drug use(r)
NGO	Non-government organisation
OVC	Orphans and vulnerable children living in a world with AIDS
PLWHA	People (Person) living with HIV/AIDS
PMTCT	Prevention of mother to child transmission
SC	Save the Children
SCA	Save the Children Australia
SCUK	Save the Children UK
SEEARO	Southeast and East Asia Regional Office (of SCUK)
UNICEF	United Nations Children's Fund
VCT	Voluntary counselling and testing

"*Children affected by HIV/AIDS*" *is used in this report to mean children directly affected by HIV/AIDS – children living with HIV/AIDS, children whose families have members living with HIV/AIDS and children who are orphans to AIDS; also included may be children living in communities of high HIV/AIDS prevalence.*

SMALL ALSO HAVE SOMETHING TO SAY...

A report on research into the effects of HIV/AIDS on children in six Asian countries

EXECUTIVE SUMMARY

"Small also have something to say..." is a Save the Children report on research into the effects of HIV/AIDS on children in six Asian countries.

This regional research, funded by the Department for International Development (DFID) of the British government, was conducted in 2005.

Background

HIV/AIDS has profoundly affected families and communities around the world and is one of the greatest threats to eradicating poverty and achieving the Millennium Development Goals (MDGs). One of the most serious challenges of the epidemic is the growing number of children who have lost one or both parents to AIDS or whose lives have been altered because of it. The number of children orphaned by AIDS is expected to exceed 25 million by 2010. This number represents a mere fraction of the number of children whose lives will have been radically impacted by the disease. This impact is reflected in the struggles faced by their families and communities and in the strains imposed on the health care system, the welfare system and on local and national economies.[1]

Within Asia, the characteristics, rates of infection and acuteness of the epidemic differ from country to country. However one constant is that the epidemic is a swiftly escalating disaster for children, not only those who are infected by the disease itself, but also those who are made vulnerable by its presence in their home or community. Despite this, there still remains a considerable lack of understanding in Southeast and East Asia about how children are made vulnerable by HIV/AIDS and the negative impacts it has on their lives.

To gain a clearer understanding of how children are affected by HIV/AIDS in the Southeast and East Asia region, Save the Children UK and Save the Children Australia, with funding from the UK's Department for International Development (DFID) decided to conduct a multi-country study to assess how the impacts of HIV/AIDS on children differ across the region. While many studies exist to illustrate how HIV/AIDS impacts on children, few of these present the situation from the perspectives of children who are vulnerable to and affected by HIV/AIDS themselves. One of the unique aspects of this research project, therefore, was the emphasis given to obtaining information on HIV/AIDS risks, impacts and responses from children themselves.

Process of the research

Initial meetings were held to determine which Save the Children country programmes would participate in the research. The countries involved were: China, Indonesia, Myanmar and Thailand through Save the Children UK programmes and Cambodia and Lao PDR through Save the Children Australia programmes.

A preparatory research meeting and training workshop was conducted in Bangkok in June 2005. Research managers and some researchers from each

participating country attended. Besides discussions of research aims, principles and methodologies, the meeting made significant decisions about the participation of children; *one major motivation for the research was to enable the voices of children in the region to be heard.*

Following this, in-country preparation included:

- Identifying research sites
- Gaining permission
- Identifying researchers
- Training researchers
- Developing questions
- Determining methodologies for research

The research was conducted between July and November 2005. 2292 people participated in the research as respondents; of these 1633 were children.

In two countries, Cambodia and China, the research was child-led, meaning that children were the researchers: they designed questions, conducted interviews and gave input into the final conclusions and recommendations. In the other four countries the research was conducted by adults. In all countries children were the primary respondents.

Research information was analysed in the period December 2005– January 2006 by various processes, including a meeting of researchers in Bangkok in December, which considered regional priorities for children affected by HIV/AIDS.

The findings of the research

The regional research aimed to find out how children were being affected by HIV/AIDS. Questions and discussions focused on: social, economic and other factors that placed children at risk of HIV infection; impacts of HIV/AIDS on affected children; children's access to services for prevention, care and support.

1. Factors that place children at increased risk of HIV infection

There is no single factor that places children at increased risk of infection with HIV. A combination of related factors all contribute to children's risk. These factors include:

- Lack of knowledge and access to information on HIV/AIDS
- Knowledge of HIV/AIDS but poor awareness of prevention and risk
- Poor literacy
- Lack of adult advice and care
- Lack of life skills
- Migration and trafficking
- Commercial sex work
- Sexual abuse
- Mother to child transmission
- Injecting drug use, use of other drugs, use of alcohol
- Early sexual debut
- Peer pressure
- Lack of emotional support

2. Impacts of HIV/AIDS on children's lives

The research found the following to be the major impacts of HIV/AIDS on the lives of children:

- Experience of discrimination and stigma, including loss of friends
- Not able to go to school, dropping out of school
- Experience serious poverty
- Having to work to support parents, siblings, family
- Need to care for their parents
- Loss of parents and change of caregiver
- Lack of adult advice
- Lack of protection
- Exploitation and abuse
- Becoming street children
- Trafficking
- Emotional and psychological problems and stress

- Substance abuse
- Social isolation
- Loss of homes and inheritance rights

3. Children's access to prevention, care and support services

Lack of access to prevention services, including knowledge and availability of condoms, is one of the factors placing children at increased risk of HIV infection. Access needs to take into account the following:

- Appropriateness, including language, clarity and interest
- Children's literacy
- Adult attitudes
- Children's embarrassment
- Distances to be travelled
- Children's availability – are they working, caring for parents, siblings?
- Promotion of the services

Other findings in this part of the research were:

- Lack of access for adults to Anti-retroviral therapy (ART), prevention of mother to child transmission (PMTCT) and voluntary counselling and testing (VCT) all impacted on children.

- Direct care and support generally came from families, friends and communities.

- There are few specific services for children and fostering mechanisms are poor, badly monitored or non-existent.

Conclusions

➢ Poor understanding of HIV and its prevention combines with lack of adequate adult care, lack of life skills and exploitation to render numbers of children at increased risk of HIV infection. Poor access to services is also identified as a significant factor increasing children's risk of HIV infection.

➢ The impact of HIV/AIDS on children directly affected by HIV/AIDS covers every aspect of their lives: economic, educational, emotional and social. Children are suffering extreme poverty and emotional turmoil, they are often exploited or shunned by others. They are not receiving schooling or their schooling is compromised by poor attendance, lack of materials or personal exhaustion. The adult care they receive is inadequate and often they are mistreated by carers. Many are growing up with little hope or happiness and feel ashamed.

➢ In every country there is some access to services related to prevention, care and support. All countries provide HIV/AIDS messages and conduct prevention activities and campaigns. The accessibility of these and their appropriateness for children differs. Prevention education is often limited by lack of geographic accessibility; prevention information often does not reach children at increased risk, such as out-of-school children and migrating children. Care and support services for children are few. Access to clinical services by adult PLWHA who are parents is important for the welfare of their children.

Recommendations

A wide-ranging research project will inevitably result in a large number of recommendations. Detailed recommendations are in the report. These recommendations are relevant to all stakeholders. Communities, donors, governments, NGOs and UN bodies need to identify how they can best contribute to reducing the impact of HIV/AIDS on children.

Summary of recommendations

- Develop and implement HIV information and education programmes specifically designed for children, emphasising clarity of messages and ease of understanding. Ensure that such programmes are widely available, especially to the following: street children, rural children, working children, out-of-school children, children who migrate and children living without adequate adult care.

- Develop and implement comprehensive programmes for children directly affected by HIV/AIDS, especially orphans and children who are carers. Such programmes need to ensure that children have access to sufficient and nutritious food, clothing, shelter, education and health care.

- Develop and monitor adequate fostering policies and arrangements, particularly to ensure proper adult care and an end to exploitation of foster children.

- Continue and increase programmes related to child protection, children's rights and to ending child trafficking and exploitation.

- Continue and increase anti-discrimination activities.

- Develop and implement life skills activities for children, recognising the special need for these skills in a world with HIV/AIDS.

- Continue and improve clinical services to PLWHA, especially those who are parents, particularly the following: Prevention of mother to child transmission (PMTCT), availability of anti-retroviral therapy (ART) and voluntary counselling and testing (VCT).

- Continue and increase the active involvement of children in HIV/AIDS activities and other activities which impact on their lives.

- ***Save the Children should continue to address some of the above through a continuing regional programming initiative and through increased activity in specific countries.***

CHAPTER ONE : INTRODUCING THE RESEARCH

Background

HIV/AIDS has profoundly affected families and communities around the world and is one of the greatest threats to eradicating poverty and achieving the Millennium Development Goals (MDGs). One of the most serious challenges of the epidemic is the growing number of children who have lost one or both parents to AIDS or whose lives have been altered because of it. The number of children orphaned by AIDS is expected to exceed 25 million by 2010. This number represents a mere fraction of the number of children whose lives will have been radically impacted by the disease. This impact is reflected in the struggles faced by their families and communities and in the strains imposed on the health care system, the welfare system and on local and national economies.[2]

Within Asia, the characteristics, rates of infection and acuteness of the epidemic differ from country to country. However one constant is that the epidemic is a swiftly escalating disaster for children, not only those who are infected by the disease itself, but also those who are made vulnerable by its presence in their home or community. Despite this, there still remains a considerable lack of understanding in Southeast and East Asia about how children are made vulnerable by HIV/AIDS and the negative impacts it has on their lives.

To gain a clearer understanding of how children are affected by HIV/AIDS in the Southeast and East Asia region, Save the Children UK and Save the Children Australia, with funding from the UK's Department for International Development decided to conduct a multi-country study to assess how the impacts of HIV/AIDS on children differ across the region. While many studies exist to illustrate how HIV/AIDS impacts on children, few of these present the situation from the perspectives of children who are vulnerable to and affected by HIV/AIDS themselves. One of the unique aspects of this research project therefore was the emphasis given to obtaining information on HIV/AIDS risks, impacts and responses from children themselves.

Introduction

This report synthesises the information collected by Save the Children in 2005 during this research project on the effects of HIV/AIDS on children in Southeast and East Asia.

The research was conducted in six countries in the Asia region. The countries were chosen on the basis of the following:

- Countries where Save the Children is currently working
- Countries experiencing different stages of the HIV epidemic.

The countries where the research was conducted are: Kingdom of Cambodia, People's Republic of China, Republic of Indonesia, Union of Myanmar, Lao People's Democratic Republic, Kingdom of Thailand.

Save the Children currently implements country programmes through Save the Children United Kingdom (SCUK) in China, Indonesia and Myanmar, through Save the Children Australia (SCA) in Cambodia and Laos and there is a special programme implemented by SCUK in the tsunami-affected areas of Thailand.

Cambodia, China, Myanmar and Thailand are countries with significant HIV epidemics, the epidemic is not as yet seriously advanced in Indonesia or Laos.

This report is primarily concerned with the following:

- The process of the research
- The findings related to children, with emphasis on allowing the voices of children to be heard
- Conclusions from the research
- Recommendations for future action and programming to mitigate the effects of HIV/AIDS on children.

Brief note on HIV/AIDS in the six countries involved in the research.

It is difficult to gain full, accurate statistical information about the HIV epidemic in all of these countries. However, UNAIDS provides some statistics which have been developed through cooperation with official organisations in each country.

It should be noted that, whilst the overall calculated percentage rate of HIV infection in China is very low, the epidemic is considered serious in five provinces/autonomous regions. Two of these areas, Xinjiang and Yunnan, were selected as sites for this research.

Table 1: HIV prevalence by country as at end of 2003[3]

Country	Estimated population	HIV prevalence (percentage)	Estimated numbers of PLWHA	Suggested main modes of transmission
Cambodia	14 million	2.6%	170,000	Heterosexual
China	1.3 billion	0.1%	840,000	Injecting drug use, heterosexual
Indonesia	222 million	0.1%	110,000	Injecting drug use, sex work
Laos	5.6 million	0.1%	1700	
Myanmar	50 million	1.2%	330,000	Injecting drug use, heterosexual
Thailand	63 million	< 1.5%	570,000	Multi–faceted epidemic

Number of orphans to AIDS

Recent estimates of numbers of children orphaned by HIV/AIDS in the countries of Asia and the Pacific indicate that by the end of 2004:[4]

- 1.5 million children had been orphaned by AIDS
- 120,700 children were living with HIV/AIDS
- 46,900 children were newly infected in 2004
- 35,000 children needed anti-retroviral therapy

However data collection on children and HIV/AIDS is not well developed, and there continues to be little clarity about the actual numbers of children orphaned by AIDS. There is an estimate of 60,000 orphans at the end of 2003 in Cambodia.[5] Thailand, where there have been an estimated 80,000 AIDS deaths, is considered to have at least 150,000 orphans.[6]

Children's workshop, Indonesia

CHAPTER TWO : CONDUCTING THE RESEARCH

Preparing for the research

This research project was conducted by Save the Children UK and Save the Children Australia across six countries. To make sure that the research proceeded as planned, a coordination team, made up of a lead regional researcher, Mr. Lindsay Daines, and Save the Children UK's Regional HIV/AIDS Adviser for Southeast and East Asia, Ms. Elaine Ireland, was appointed to guide the research.

What makes this research important?

This was a multi-country research process ranging across six countries with very differing epidemics but with the common factor of assessing the effects of the epidemic on children. The participation of children as the main response group to the research also makes this research significantly different to other research projects being carried out in the Southeast and East Asia region. In two countries, Cambodia and China the research was child-led, a major achievement especially in a research project of this size.

Regional research framework

To guide the research and ensure all countries were working towards common aims and using comparable methodologies, a draft research framework was developed. The purpose of this document was to outline the process and stages of the research project. As the research was regional, the framework was developed as a means of ensuring consistency of practice and similarity of information collected, whilst at the same time allowing for differences between countries.

The framework was discussed in detail at a regional training and planning workshop in Bangkok in early June 2005 when final research priorities and strategies were determined, research tools discussed and training in undertaking research was conducted. Following this meeting the framework was re-written into its final format and distributed as a guiding document for the multi-country research.

Children's discussion, Cambodia

The final framework document contains information on the following:

- The situations the research explores
- Coordination of the regional research
- Stages of implementation
- Preparation
- Data collection
- Analysis of the data
- Reporting

Participatory, child-centred research

A major aim of the project was to find out the views of children. *As the research was about the situation of children, it was agreed that children should be the primary focus of all our research work and that mechanisms should be put in place to ensure the broadest possible participation of children.* One concern of the workshop was how to develop a research plan that was participatory and action-based. The workshop included intensive analysis of levels of participation, participatory research and how this research would involve children as widely as possible.

At a regional training workshop held in Bangkok, representatives from SCUK in China presented their experiences of conducting child-led research. There was considerable discussion of this method and most country teams left the workshop having decided that they would try to use child-led research in at least some of their research sites.

Training the Research Teams

To ensure all research coordinators were fully prepared to conduct this research project, a regional workshop was held in Bangkok in June 2005. This workshop was attended by the in-country managers of the research and by some of those responsible for the preparation for and conduct of the research in the six participating countries.

The training workshop programme included:

- Discussion of the draft research framework
- Some underlying principles of research
- Presentations of HIV/AIDS situation in the participating countries
- Researching with children
- Techniques for working with children
- Developing interview questions
- Developing other strategies for research
- Interview techniques
- What to read
- Planning your research in-country

Much of the workshop was spent exploring ways of working and researching with children. There were various exercises related to the use of techniques like role play, drawing, and mapping. These exercises in themselves were participatory with workshop attendees doing the exercises and then discussing in detail the implications for using specific techniques in their own countries.

Developing research questions

Another major component of the workshop related to the development of draft questions for interviews and focus group discussions. Small groups worked on developing questions for the three topic areas of the research:

- the factors that place children at risk of HIV infection
- the impacts of HIV/AIDS on children's lives
- children's access to prevention, care and support services.

Draft sets of questions were developed and discussed. It was acknowledged that the development of questions would take much more time than was available during a workshop, however the activity and subsequent discussions helped participants understand the complexities of developing questions and gain a greater understanding of the questions to include in the research.

Research aims and principles

A brief guiding document comprising a summary of aims and principles was developed by the end of the workshop. Along with the framework this summary was designed to ensure consistency of research practice and information collected in the six participating countries.

This summary of aims and principles is included as an annex.

Deciding the sample size

After much discussion and taking into account the fact that the research was to be qualitative in nature, it was decided that there should be around 200 respondents in each country, this number was to be made up mainly of individual interviews but would include information gathered though other methods such as focus group discussions. The respondents for the research included children at risk of HIV infection as well as those living with and affected by HIV/AIDS, along with key adult stakeholders, such as parents, teachers, and government officials.

In-country research training plan

After the regional training workshop and in response to several requests, the consultant developed and distributed a plan for in-country training of researchers. The document contained suggested structure and content for a two to three day training workshop for local researchers; the document expanded on and clarified some of the exercises used at the Bangkok workshop.

Topics included:

- Revision of HIV/AIDS
- Purpose of the research
- Participation
- Underlying principles
- Researching with children, including methods for working with children
- Using interviews and small groups discussions
- Developing questions

Developing the research in-country

Preparation

Most country research teams have reported that the development of the research in-country took much longer than expected. The stages in the development of the process included:

- Identifying research sites
- Gaining permission
- Identifying researchers
- Training researchers
- Developing questions
- Determining methodologies for research

Identifying research sites

Countries involved in the research are experiencing the HIV/AIDS epidemic at different stages. In Cambodia, Myanmar and Thailand and some parts of China the epidemic is advanced; in Indonesia and Laos the epidemic is in early stages. In Thailand, whilst the country is in an advanced stage of the epidemic, the area where the research was conducted, an area seriously affected by the 2004 Asian tsunami, is not considered a high-prevalence area.

The aim of the research was to identify the effects of HIV/AIDS on children in different situations, so it was essential in each country to identify a variety of research sites. The limitations on this were time and money: there was neither enough time nor money to carry out qualitative research in large numbers of sites. Each country team chose research sites which reflected the various stages and nature of the epidemic in that country.

The selection of sites took into account the following:

- HIV/AIDS prevalence
- Areas where there are high numbers of mobile people
- Areas where large numbers of children are living in extreme poverty
- Areas with poor services in health and education
- A mix of rural and urban population areas
- Areas where Save the Children has permission to work
- Considerations of ethnicity and religion

The significance of the above in determining final decisions differed between countries.

In countries with low HIV prevalence research was conducted in at least one of the areas of high prevalence for that country (for example: Jakarta in Indonesia and Savannakhet in Laos). In Cambodia, China and Myanmar research was carried out in areas of high or medium prevalence. The research in Thailand was specific to an area affected by the 2004 tsunami.

A total of 57 sites were selected for the research study. China carried out research in six sites, Indonesia in 10 sites, Cambodia in six sites, Laos in 19 sites, Myanmar in six sites, and Thailand in 10 sites. The numbers of respondents in each site differed.

In all countries there was a balance between rural and urban sites. In Cambodia, China, Myanmar and Thailand research was carried out in areas where SC had already been working. In Indonesia the sites were primarily in areas where SC is working or in some cases in areas neighbouring SC-targeted areas. In Laos SCA decided to work with Laos Red Cross as a partner, some sites were therefore in areas where SCA had not previously worked.

Gaining permission and cooperation

Gaining permission to carry out research was an essential feature of the process. Already having an acknowledged presence in an area selected for research was important to ensure that there were no long delays in setting up the research process. For example, in Cambodia SCA was already working with Buddhist monks and with government permission in all the selected sites. However, in Laos site selection depended on the association between SCA and Laos Red Cross; this had consequences for the actual implementation of the research project.

In each site SC worked with government officials and local NGO and community partners in ensuring community and official cooperation to carry out the research. Partners and supporters are indicated in the following table.

Table 2: Provinces and number of sites in which research was conducted

Country	Provinces	Number of sites
Cambodia	Phnom Penh Siem Reap Takeo	2 2 2
China	Xinjiang Yunnan	2 4
Indonesia	Ambon Belu Jakarta Kupang Pemangkat	3 3 1 1 2
Laos	Bokeo Khammoune Savannakhet Sayaboury Vientiane	3 2 2 3 9
Myanmar	Karen Mon Northern Shan	2 2 2
Thailand	Phangnga Phuket	9 1

Table 3:	Partners cooperating with SC in the research
Country	**Partners /Supporters**
Cambodia	Selected Buddhist pagodas, in cooperation with government, especially Ministry of Culture and Religious Affairs
China	Yunnan Education Department, Yunnan Women's Federation, Xingjiang Women's Federation
Indonesia	Offices of Education, Komisi Penanggulangan AIDS Daerah, local NGOs
Laos	Laos Red Cross
Myanmar	Existing community structures where SC already works
Thailand	Existing community structures and local NGOs with whom SC already works

Selection of researchers

Each country appointed a research manager and research coordinator. In most situations these were SC staff members. Two countries, Cambodia and China, conducted child-led research, in both countries the child-led research was coordinated by SC staff or researchers appointed by SC. *As child-led activity and research are generally new concepts in this region, it is important for this report to refer to specific features of the child-led research process.*

Child-led research

Child-led research is a new activity in many countries. In child-led research it is children themselves who are the main researchers. They decide the questions, collect the information and even analyse the data. The aim is the empowerment of children to speak and act for themselves and for other children. Of course, in most instances the research needs to be guided by adults: adults need to be there to support children's rights to develop and conduct their own activities, adults are there to assist with problems. Ideally however the children make decisions for themselves.

> *"How many times have we heard adults speak on behalf of children, deciding on the needs and interests of the ones not given the chance to express themselves. The truth is that children are not usually asked for opinions on the matters that affect them. It is taken for granted that adults know best what the needs and interests of children are."*[7]

In Cambodia, where SC has worked closely for a number of years with Buddhist pagodas in areas of high HIV prevalence, monks at the six sites selected children aged 12-17 years from whom the researchers were chosen. The children then elected those who would become the researchers. At each site six children were selected to be researchers, a total of 36 researchers; there was equal gender balance. All of the children selected came from families affected by HIV/AIDS.

In China the child researchers were selected by adults. In Xinjiang the selection of 30 children was carried out with the assistance of the Women's Federation. A total of 19 girls and 11 boys were chosen. In Yunnan the Yingjiang County Education Bureau and the County Women's Federation selected 13 girls and nine boys as researchers.

Child researchers, Siem Reap, Cambodia

Selecting child researchers in Cambodia:

The child researchers were selected by their peers in their community.

At each site 6 children were selected which means that in all they were 36 child researchers. Criteria for child researchers:

- *12-17 years old*
- *Gender balance, 3 boys 3 girls*
- *OVC (orphans and vulnerable children group)*

From the former information day the children knew about the purpose of the research and what the role of the child researcher was and by the end of that day they were asked to go home and think if they were interested in becoming a child research assistant. What surprised us when we came back a week later was the overwhelming interest by the children to become child researchers, we had expected that maybe half of the children would be interested but at all of the sites the majority of the children volunteered. We asked the children that volunteered to introduce themselves and say a few words of why they wanted to become child researchers.

"... I want to be a child researcher to talk to children and help poor children in my community"

"...I want to be a child researcher to get more knowledge about HIV/AIDS"

Process of the selection:

- *The candidates were provided with a number to hold in front of them*
- *The children voted by writing down four numbers on a piece of paper of their preferred candidates, 2 boys and 2 girls, the candidates also voted*
- *The votes were put in a closed box*
- *When everybody had voted the votes were read out and counted by two volunteers.*

The votes were anonymous and the children voted in silence. They took the election very seriously, and the majority had never participated in anything like this before. To ensure a fair election, the process was supervised by the adults.

After the election we spoke with all of the children to inform them that even if you did not get selected as a researcher if you want to, you can still be an important part of the study as a respondent.[8]

In the other four countries the researchers were adults. In Indonesia, Myanmar and Thailand researchers were selected by SC. In Lao PDR researchers were selected by SC and Laos Red Cross.

Gaining permission to conduct the research

In most countries, as the research was being conducted in areas where SC already has "permission to work", there was no special permission needed.

In Laos, as mentioned above, SC needed to work with the Laos Red Cross, which is a government organisation. Whilst this was a necessary strategy it led to the Red Cross making decisions which were outside the suggestions of the research framework. A decision to work with far more respondents than had been suggested in the framework affected the research process and outcomes.

Permission for child-led research:

In Cambodia once the child researchers had been selected, adult members of the SC research team visited the parents or care-givers to explain the research and ask permission for the children to participate. In China, where there was not an election process, selection had already been done and permission gained by those who selected the child researchers.

Training researchers in-country

The six participating countries in the research conducted training workshops and held meetings with local researchers involved in the project. The content, format and length of the workshops differed from country to country, although most were of two to three days' duration. The workshops were based on the model circulated to participating countries. All researchers were trained in the purpose of the research, principles underlying the research and research methods.

Training of child researchers:

Workshops were also conducted in Cambodia and China for children who were to be researchers. Whilst similar in content to the adult workshops, being for children, there was more emphasis on "fun" activities and child-focused learning and activity. There was wide use of activities such as games, puzzles, drawings and role play. Nevertheless the workshops also included a lot of information about HIV/AIDS and focused on training children in interview techniques. In China the child researchers were trained to become "little journalists".

> *"I'm very willing to attend such activities since they can improve our independent thinking and presentation skills"*
>
> Comment from participant in child-led research training workshop in Yunnan, China [9]

Developing Questions

The development of questions for individual interviews and focus groups discussions was a lengthy process. In most countries the development of questions took place at the workshops for training researchers. Questions were developed around the three focus topics for the research.

In Indonesia, Laos, Myanmar and Thailand questions were developed by the research teams then forwarded for comment to the regional adviser and research coordinator. Once these comments were received the questions were revised and then field-tested with groups of children. Then a final collection of questions was created.

In Cambodia the questions were developed by the child-researchers. Following an introduction about HIV/AIDS and the three topic areas, the researchers developed questions individually and then discussed them with each other, finally selecting over one hundred questions. These questions were then discussed and edited by a panel of adults into about forty questions. These questions were then field-tested with the child researchers after which some questions were revised, omitted or added.

In China the process was a little different. As the adult research team wanted the questions to come from children without too much instruction, the children developed questions focusing on the broad topic of the major concerns, worries and dreams of children. There was no specific focus on HIV/AIDS. However, as the research was to be conducted in areas of relatively high prevalence, this lack of specificity was not seen as a problem. The questions were developed by a method of ranking issues of major concern to children and then developing questions related to these issues.

Determining research methodologies

Methodologies for use during the research were tested during the in-country training workshops. After these, discussions and final methods of data collection were decided on.

In four countries research teams used in-depth individual interviews as the main means of collecting information. In Laos and Thailand in-depth interviews were conducted with some respondents, but a lot of the information was collected as part of focus group discussions which took place during workshops with children. Focus group discussions were also a means of information collection in other countries. Other activities used to collect information and used to begin discussions of issues included: drawing, games, mapping, photos, problem trees and role plays. These tools for data collection were decided on before the research began. In general games, drawing and mapping were used to collect information from younger children; focus groups and interviews were used for older children and adults.

Conducting the research

The research period was between July and November 2005. While the research teams in China were fairly quick in collecting the data, countries where the research sites were distant from each other or where many respondents participated took a much longer time to collect the information. Some countries experienced unexpected problems in collecting data. For example in Cambodia, the availability of children to do the research sometimes posed problems as child researchers could not miss out on school and so research needed to be conducted at weekends. Most countries were ready to begin analysing data by November.

Who participated in the research?

The findings which follow are based on information provided by hundreds of children and adults who participated in the research between July and November 2005.

A total of 2292 persons participated in the research as respondents. Of these 1633 were children, representing over 70% of the total number of respondents. In Cambodia, China and Thailand children made up between 75% and 82% of the total respondents. In Indonesia, Laos and Myanmar children made up between 62% and 70% of the total respondents.

Table 4: Research periods

Country	Research period – data collection
Cambodia	September - November
China	July, August
Indonesia	August - October
Laos	August - November
Myanmar	July - October
Thailand	August - November

In-depth interview, China

Table 5: Respondents					
Country	**Number of Children**	**Female Children**	**Male Children**	**Number of Adults**	**Total Respondents**
Cambodia	180	90	90	46	226
China	306	107	110	68	374
Indonesia	202	109	93	142	344
Myanmar	220	112	108	108	328
Laos	614	306	308	267	881
Thailand	111	62	49	28	139
Totals	1633	786	758	659	2292

[Note: Gender of child respondents was not completely recorded in all sites]

Most of the children who participated as respondents were living in poverty and/or belonged to the group "children in difficult circumstances". Adults interviewed were drawn from a wider range of social and economic groupings and included NGO workers, social workers, government officials, caregivers and people living with HIV/AIDS (PLWHA).

In Cambodia, China and Myanmar many respondents came from high prevalence areas. Indonesia and Laos are low HIV prevalence countries. Thailand is a high prevalence country, but the research took place in an area where HIV/AIDS was not necessarily a significant problem.

Challenges faced during the data collection period

Researchers faced numerous challenges during the period when they were carrying out the actual data collection. The most commonly mentioned challenge was the problem of limited time. Time constraints came about for a variety of reasons, often related to the following:

- Time it takes to gain permission to undertake the research and to work closely with children. (For example in Laos it took

considerable time to explain the purpose of the research).

- Time it takes to adequately prepare for working with children. Children are generally not used to being consulted so are often reticent; this takes time to overcome. In addition it takes time for children to relax.
- Time it takes to negotiate with local partners and "gatekeepers"
- Meetings with working children are often difficult to organise
- Children are busy; often in school

Other challenges were:

- Attitude of adults to children conducting research or being participants in research activities
- Culture of parental control over children
- Discrimination and stigma mean people are often unwilling to talk about HIV/AIDS
- Cultural traditions of not talking about sexuality
- Venues for the interviews and discussion groups – in some sites the meetings lacked privacy
- Some children did not see the research as important – children do not know what the results of research might be. In Thailand, for example, the tsunami-affected area is the subject of much research and people's lives are often being researched; they ask: "How will this improve things for us?"

Some successes during the research process

Despite some challenges, all country teams spoke of the success of working with large numbers of children.

In Indonesia, Laos, Myanmar and Thailand the participation of children in the research was highlighted as a significant step in listening to the voices of children.

"Children and youth played a key role in the success of this research because they are willing to participate and give a lot of information" [10]

"Activities (in this research) can become a tool to mobilise children in more positive activities" [11]

"We empower children to be able to speak up and communicate their ideas among themselves" [12]

Quotes from adult researchers in Indonesia and Thailand on the value of involving children in research.

Role-play during children's workshop, Thailand

In Cambodia and China the child-led research had a considerable impact on communities and the children themselves.

"We are impressed by the capacity of the child researchers; it has been interesting to see them grow from shy and quiet at first....to confident, lively children not afraid to express their ideas and opinions" [13]

Adult researchers in Cambodia

"I'm very excited. I learn a lot from it"

"It helps me know something that I have never known before. I learn how to cope with difficulties and overcome them and it is my responsibility to help others." [14]

Child researchers from Yunnan, China

Some other comments on the participatory approach

"I am very glad to know that my children are offered opportunity to take part in this workshop" [15]

Comment from parent in Xinjiang, China

"When we reach for a participatory approach and a high involvement of children we need to take into consideration that the process will be more time consuming ...for good participation we must allow every part of the process to take its time" [16]

"A participatory approach requires an environment where the participants feel safe and confident. It takes time to build up such an environment" [17]

Comments by adult researchers in Cambodia

Lessons learned from children's participation and child-led research

- Children should be free from the influence of adults when participating in research.
- Children are more open if few adults are involved.
- Many adults do not believe in children's ability, so it is important to explain to adults including community leaders, NGOs and government, why we are concentrating the research on children.
- Developing children's participation is a gradual process – aim for the widest and most meaningful participation possible.
- Allow time for activities with children. Time is needed to explain clearly what we are doing. Time is needed to meet with children. **Children are often busy.**
- Even as researchers, children still need adult support. Adults should be there but in the background.
- Children's safety as researchers and respondent is an important concern. Ensure proper understanding of child protection and children's rights by children and supportive adults.
- Children are happy because they are being consulted and are doing something (child researchers).
- Children should be told the results of research in which they have participated.
- Children's participation needs to involve different activities – use games, drawings, role play to relax and interest children.
- Children may become sad when discussing difficult issues related to their lives.
- Children often have a deep understanding about the societies in which they live; they are frank about their lives and the lives of other children.
- Many adults were very cooperative with child researchers and admired their work.
- "Some adults accepted our interviews with tears in eyes"[18]

Children's honesty and simplicity are to be highly valued.

Analysing the data

A data analysis guide was developed by the lead researcher and the regional coordinator and circulated to the in-country research teams for guidance.

In China the data was analysed by the child researchers with the assistance of the adult research team. In the other five countries the analysis was undertaken by the adult researchers, in some countries this involved all the main research team, in others only a selected group. In Cambodia, where the research had been carried out by children the analysis did not involve the child researchers due to time and logistical constraints. However, summaries of the research results were shared with child researchers for comment.

In all countries the data analysis process was time-consuming especially in Laos where the research had a large number of respondents. In general the in-country analysis took at least four weeks.

Compiling the regional findings

Having completed the data analysis, draft country reports detailing findings of the research were written. These reports formed the basis of the discussions at a meeting of key members of the country research teams in Bangkok in December 2005.

Those attending the meeting looked at the issues that were of most importance in their country and within the region. Clearly there were major differences between country findings, however a number of issues related to HIV/AIDS and children emerged as common. Comments on the draft reports were taken back to countries and country reports were finalised by late January 2006.

The findings of the country research reports and the major issues identified at the December Bangkok research meeting make up the extensive findings of this regional report on the effects of HIV/AIDS on children in six Asian countries.

Analysis discussion, China

Children's workshop in China

CHAPTER THREE : HOW HIV/AIDS AFFECTS CHILDREN IN SOUTHEAST AND EAST ASIA

This chapter provides an extensive discussion of findings from the regional research conducted by SCUK and SCA in 2005. Findings highlighted here are based on country research reports and the outcomes of discussions from the regional data analysis workshop held in Bangkok in December 2005.

The research concentrated on three topic areas about which information was sought. These topic areas are:

- the factors that place children at risk of HIV infection,
- the impacts of HIV/AIDS on children's lives,
- children's access to prevention, care and support services.

Included in this chapter are numerous quotations mainly from children who were respondents. It is important that we hear these voices as they represent the views of many other children and adults who participated.

A. Factors that place children at risk of HIV infection

Based on in-country findings, the discussions in Bangkok listed the following as key factors that place children at risk of HIV infection:

- Poverty
- Lack of knowledge and access to information on HIV/AIDS
- Lack of life skills
- Poor literacy
- Lack of adult advice
- Knowledge of HIV/AIDS but poor awareness of prevention and risk
- Migration and trafficking
- Commercial sex work
- Sexual abuse
- Injecting drug use, use of other drugs
- Tattoo
- Early sexual debut
- Peer pressure
- Lack of emotional support
- Family violence
- Poor health care system
- Alcohol consumption

In discussion it was agreed that poverty was a defining issue and was responsible for most of the problems faced in developing countries. Poverty was the cause of many, though not all, of the other factors listed. It was agreed that, whilst addressing poverty was of over-arching importance, this research and its conclusions would try to find solutions to more specific problems.

All countries listed the following as of major significance in increasing the risk of HIV infection among children:

- Lack of knowledge/access to information about HIV/AIDS
- Migration and trafficking
- Lack of life skills
- Peer pressure

All countries listed the following but with differing degrees of significance:

- Alcohol consumption
- Poor health care systems

In four or five countries the following were considered very significant:

- Sex work
- Early sexual debut (as sex workers or with "lovers")
- Lack of emotional support
- Lack of adult advice

Whilst it is difficult to make too many generalisations from these conclusions, it is clear that in different situations all factors are significant. Some factors, such as sex work or family violence, may not have been mentioned in certain contexts because they are "taboo topics".

Focus group discussion with children in Indonesia

What makes children vulnerable to HIV infection?

Lack of knowledge of HIV/AIDS and access to information remains a major factor in increasing children's vulnerability to HIV infection.

Research in all countries revealed generally superficial knowledge about HIV transmission among children and adults. Country reports indicate this, the following are some examples.

In Myanmar 90% of respondents reported having heard of HIV/AIDS, mainly from mass media, health education talks and friends. However just under 10% had never heard of HIV/AIDS.

The Myanmar report states what seem to be true for all countries surveyed:

"People may have heard of HIV/AIDS but that does not necessarily mean a good knowledge about it. Overall, the respondents were knowledgeable about the major modes of transmission, but they still had misconceptions about mode of transmission and the likelihood of transmission through casual contact." [21]

There are many barriers to the acquisition of clear and correct knowledge.

> *"I've never heard of HIV/AIDS and never seen a patient. No one has ever told me. In school, no one comes and teach us either".*[19]
>
> 8 year old girl, 3rd grade student from Mon State
>
> *"I haven't heard anything about that disease. In our village, there was once an exhibition. They set up many pictures and posters but I didn't go inside to see. I can't read and write so I dare not go in. The same are my friends. They can't read too. So they didn't go in, either."*[20]
>
> 14 year old girl from Northern Shan State

"Almost every villager now has heard about AIDS. But I think few understand the details clearly. They live far away from town and the transportation is very difficult. It's impossible to reach them clear information. In fact it would be only superficial knowledge. Those who know well have attended seminars and workshops. Young people from the village are farmers; they have to work in the field all day long. They can't spend the whole day at the workshop even if they go at all. So they don't know much. They are embarrassed when the talk gets round to condoms".[22]

17 year old Karen female, casual worker who plans to go to the neighbouring country

"I heard people saying about the disease, but I don't recognize how it spread or can be prevented. Some people from an organization came to invite me to the health education session once. But my father didn't allow me to go. He just asked me to go to work. He said to them I was busy. In fact, I wanted to go and listen. But if I don't work one day, we won't have any money to buy food for that day."[23]

15 year old boy working in a construction site in Thaton

In Cambodia around 30% of children believed that they can be infected with HIV through mosquito bites. Being infected by holding hands, kissing HIV+ parents or playing with HIV+ children was a fear expressed by 10% of Cambodian children.[24] In Indonesia there were fears among adults and children of HIV transmission through sweat and "chair used by PLWHA".[25]

The Cambodian and Indonesian examples reveal poor knowledge of transmission. The specific examples may not reveal children at risk of infection. However, poor knowledge indicates a low level of understanding of transmission; this is a major cause for concern.

In all cases these examples of poor knowledge may lead to discrimination. The fact that some children feel "unsafe" touching their parents if they have HIV creates unnecessary stress in situations which are already very difficult for children. In addition these same children are probably suffering some sort of discrimination because they are directly affected by HIV.

In Thailand, while almost all children in school understood that HIV transmits through sex and can be prevented by using condoms, there was still widespread misunderstanding of transmission – 45% believed that HIV was transmitted by mosquitoes and 39% thought that sharing a meal with someone with HIV was risky.[26]

Poor knowledge leads to fear and discrimination and fuels social rejection which may place children at greater risk of infection.

Migration and Trafficking

Whilst every country delegation at the regional data analysis workshop listed migration and trafficking as an issue, comments about this differed widely.

Migration takes place within and between countries.

In Cambodia it was commonly reported that the search for work sees many men from rural areas moving to urban areas; this internal migration for work is sometimes seasonal sometimes for long periods. The respondents believe the biggest risk for children to become infected by HIV/AIDS is through mother to child transmission. They mention that HIV first usually comes from the father who gets infected while he is working away from his home. In many cases children have experienced the father returning home and passing HIV to the mother who may then pass it to newly born babies.

The father goes out of town, he meets sex workers and when he comes back he gives HIV/AIDS to the mother.....
...The mother breastfeed her baby and she has no medicine so she gives HIV/AIDS to the child

Summary of statements by children in Cambodia[27]

More than 60% of respondents in Myanmar expressed the view that HIV/AIDS was strongly related to those who migrated to neighbouring countries.[28]

Cross border migrants from Myanmar go to Yunnan, China and Thailand. People often migrate illegally. Often female migrants end up in prostitution.

> *"I went to Thailand with two of my friends, when I was 13 years old. The broker sold me to a brothel in Mae Sod and I had to work there for four years. I did not know how to go back. But one day, I got contact with my mother and she came to Mae Sod to bring me back. Then I slip out from the brothel while the old lady went to the market."*[29]
>
> 22 year old girl living with HIV/AIDS, PLWHA, from Hpa an, Myanmar

Truck drivers through the China-Myanmar border in Myanmar's Northern Shan State often engage in casual sex. Often girls and young women are making a living from sex work in these border areas.

> *"A Shan girl opened a food stall alongside the road. She gets acquainted with drivers and truckers and then sleeps with them. Then, she earns money. She doesn't use condom, instead receives contraceptive injection. Another two Kachin girls are doing the same like her. They sell food wearing beautiful clothes and make-up. They are beautiful. Their age is around 17 or 18."*[30]
>
> 17 year old Palaung boy living near the border check point

The effects of migration on children and the actual migration of children are both factors increasing children's vulnerability to HIV infection.

Selling children for sex at home

A type of trafficking is selling children for sex at home. This was mentioned many times during the Indonesian research. A dealer identifies a girl with potential usually aged 12-15 years then approaches the parents who persuade the girl to receive a "guest". Having received one guest the girl will often receive others.

> *" yes, I know some girls, older than me, receive some 'guests' in their house... of course father and mother knows, they're at their own house".*[31]
>
> From focus group discussion of girls aged 10-14 years in Indonesia.

There was perhaps not enough research conducted on children affected by migration or being trafficked, but it is clear that these are important issues affecting children's vulnerability to HIV infection.

Vulnerability and where children live

What is also clear from a consideration of all the country research reports is that where children are living places them at increased risk of HIV infection. *Geographic location of their homes is a significant factor in placing children at risk.*

In Cambodia children identified street children and those who migrate to find work as some of the most vulnerable.[32] Street children and children living in areas with high incidence of injecting drug use are identified in the China reports from Xinjiang and Yunnan as being at particular risk of HIV infection.[33] The report from Indonesia identifies street children and children living near brothel areas, ports and areas with high incidence of injecting drug use as at greater risk of HIV infection.[34]

In Myanmar areas with high incidence of prostitution and border areas are seen as areas of higher risk for HIV/AIDS.[35] The report also points to the situation of children living in families which use drugs and the possibility that this will result in children themselves becoming users.

The conditions and surrounding areas of temporary shelters in Thailand after the tsunami were considered to be places of potential risk of HIV infection for children and young people. Separated children living in these settings were felt to be at higher risk of abuse and exploitation.[36]

Commercial sex work

Sex work has long been considered a major risk for HIV infection. The research supported this view. Children involved in sex work were interviewed in

Indonesia and Myanmar. Besides the example above, the Indonesian research team interviewed children who had been recruited as domestic workers to Malaysia and were "plunged into the prostitution business" as well as child transgender sex workers in Ambon.[37]

Child prostitution emerges as a major risk factor in the Myanmar report.

> *"When I was fourteen, both of my parents passed away from AIDS. My mother was a prostitute. When they died, the pimp family with whom we lived, drove me out. I had no where to go and sat on the road. There, I met with "Mommy". She gave me some encouraging words and took me to her house. When I turned to fifteen, Mommy asked me if I wanted to work. Afterward, I got into this business"[38].*
>
> 18 year old sex worker from Thaton.

Peer pressure and early sexual debut

Many of the comments relating to the early sexual debut of children have come from adults. Whilst it is clear that some children are having sex at early ages, it is not clear how widespread this is.

It is difficult to get children to talk about their sexual experiences and in this region researchers probably also feel constrained. *It is unlikely that child researchers will ask questions related to children's sexual experiences.* It is clear from comments by children and adults that peer pressure can be a significant influence.

In Cambodia adults interviewed saw significance in peer pressure on children to have sex at an early age. Adults felt that children are having sex early because of the influence of "foreign culture". Adults also felt that children are not afraid of HIV/AIDS because of poor knowledge or not believing in the disease.[39] This is partly contradicted by the results of interviews with children. The differences cannot be easily explained. Children generally considered HIV as a problem in their lives; adults, perhaps in order to explain what they perceived as early sexual behaviour, were looking for reasons.

Children in two sites in Indonesia spoke frequently about early sexual behaviour, but they talked about the behaviour of their friends, possibly not wanting to own up to such behaviour themselves. Children interviewed in Indonesia indicated that boys become sexually active as young as 15 years, normally with girlfriends or with sex workers.[40]

In Myanmar most comments about early sexual behaviour came from adults, however a few children's comments are significant.

> *"My friends once took me to a house where they arranged with a girl. She was in the room. They told me to go inside. They said, "Do it. Go. It's good! Don't be afraid. We'll wait for you outside".[41]*
>
> 16 year old boy from Mawlamyaing
>
> *"Sometimes my friends got some money and then we get drunk. Once, we also call a girl. I don't know where they found that girl. After that, one of us let us do it with the girl in his house. We took in turn with the same girl. I've heard of condoms, but I've never seen one. At that night, we, four of us friends did not use any condoms."[42]*
>
> 15 year old out-of-school boy from Thaton

In these examples note the mention of peer pressure, the use of alcohol and lack of condom use.

The research from Thailand reports the following:

"10-12 year old couples are like "puppy love" and talk to each other on the phone. The 13-15 year old couples may start to go out together and those older than 16 years may have sexual relationships"[43].

Research into the sexual behaviour of children is difficult, especially in this region.

The above factors are compounded by the following:

Lack of adult advice and emotional support

Street children lack advice and emotional support from adults and are subject to sexual exploitation and violence. Natural and man-made disasters have effects on the way people behave. Orphaned children in the tsunami affected areas of Thailand may be at risk of exploitation.

"The community leader said that after the tsunami, most people concentrate on rebuilding the house and boats and finding income. Together with the stress and psychological impact from the disaster, the family might not have enough time to look after their children."

"Children who are orphaned move in with relatives and in some cases do not feel comfortable ...a girl consulted the NGO worker that she is not comfortable when her uncle looks at her when she is changing her clothes"

From the research report for Thailand[44]

In Cambodia: "children say that they need proper adult care and advice. A majority of respondents believe that orphans and street children are more vulnerable to HIV/AIDS because there are no adults to look after them."[45]

The report from Xinjiang found that "Without guidance of adults, children cannot way themselves out when trapped in difficulties and they are prone to be trapped by bad practices."[46]

The China and Myanmar reports refer to parents who do not think that knowledge is important and therefore do not think schooling is important for their children.[47]

The Indonesian report refers to the "walled communication between parents and children."[48] This means children may be easily exposed to sexual lives without any proper information about sexuality.[49]

Failure to use condoms and lack of condom availability

Awareness of condom use as a means of HIV prevention is generally high. In Myanmar the research found that children were more aware of condoms than adults. This does not mean that condoms are used.

In Thailand research reveals that less than 50% of children and young people use condoms during their first sexual experience. Among the more sexually experienced only 18% used condom "every time".[52]

"When I went to a tea shop with my mates, we saw a girl sitting next to our table. She was very pretty. One of my mates show some signals to her and made a deal. Then, four of them went with her. They said they didn't use condom. None of them. They said the girl we slept with has no disease. You can see how beautiful she is and thus for sure she's clean".

They said they never get wrong and know the girls very well."[50]

17 years old Kachin boy from Nam Phartkar

"Sex can happen anytime; condom use is not always possible. In town, it's easy to get hold of condoms. But along the road, they don't have condoms and they will just have sex without condoms." [51]

18 year old boy from Shan State, working as a bus conductor

In Laos 70% of children aged 11-14 years and 85% of those aged 15-18 understood that condoms could prevent the spread of HIV[53].

Use of drugs and alcohol

Many children in all research countries knew that injecting drug use may be a risk activity for HIV/AIDS. Children also understood that the use of non-injecting drugs and alcohol could be a co-factor in transmission risk.

Injecting drug use is a major factor in the spread of HIV in China, Myanmar and Thailand; there is evidence of increasing IDU in Indonesia and IDU is emerging as a problem in Cambodia. In Laos 70% of children aged 11-14 years and 85% of children aged 15-18 identified "drug abusers" as a risk group for HIV infection.[54]

Whilst the numbers of children using injecting drugs may be low, there is increasing concern about the use of other drugs and alcohol. In Cambodia street children were viewed at risk because they are exposed to drugs.[55] In some research sites in Myanmar it was reported that children begin using drugs at age 14 or 15 and some change to injection.[56] In China there were instances of children who used drugs and some fears expressed that children living in families where drugs are used may themselves begin to use drugs.[57]

In Indonesia several groups mentioned drug and alcohol use as a risk factor and street children were seen as "prone to drug use and addiction", ranging from glue sniffing to injecting drug use.[58]

Several children in the Thai research said that although drugs and alcohol do not transmit HIV directly, they "can make you lose conscious and do things ...such as unprotected sex".[59]

So whilst injecting drug use among children may not currently pose a major risk for direct HIV transmission, the increasing incidence of drug abuse among children is a co-factor in infection.

Lack of life skills

Adults and researchers present at the regional analysis meeting identified children's lack of life skills as a major risk factor of HIV infection for children. Children did not specifically identify this, however many examples in the reports point to a lack of life skills and the relative helplessness of children. Children report physical and verbal abuse and even sexual abuse, which they feel powerless to do anything about.

Child researchers in Cambodia were afraid adults would try to get confidential information from them – "What if the adults get violent?"[60]

"My uncle often abused me sexually...Grandma didn't believe me ...I ran (away)"[61]

Children in Xinjiang, China, report mockery by teachers because of their poverty.[62]

Summary of the factors which put children at risk of HIV infection

There is no one single factor which is the prime risk factor for children. There are factors and co-factors and they differ between countries and from individual to individual.

Reporting on a group of children in Kupang, Indonesia the researchers concluded:

"All these vulnerabilities (pre-marital sex, drug use, alcohol, STIs) and risks entangled with lack of knowledge of health reproduction and HIV/AIDS (among adults and children) as well as walled communication between parents and children and the unavailability of accessible correct information increase children's vulnerability to HIV/AIDS."[63]

We can add to this list: the failure to use condoms, migration, sexual exploitation and lack of adequate adult care.

All these factors have been discussed by many children in the six countries during the research process.

B. Impacts of HIV/AIDS on children s lives

The most important aim of the research was to hear from children about the impact that HIV/AIDS has had or may be expected to have on their lives or the lives of other children.

Whilst children have a lot to tell us about their own risks of being infected by HIV, they have so much more to say about how HIV/AIDS affects them. This was particularly so of children living in the countries with developed epidemics: Cambodia, China, Myanmar and Thailand.

From the initial research findings shared at the regional data analysis meeting in December 2005 the following were highlighted as the major impacts of HIV/AIDS on children's lives:

- Experience discrimination and stigma
- Not able to go to school, dropping out of school
- Experience serious poverty
- Having to work to support parents, siblings, family
- Need to care for their parents
- Change of care giver
- Loss of parents
- Lack of adult advice
- Lack of protection
- Exploitation and abuse
- Becoming street children
- Trafficking
- Emotional and psychological problems and stress
- Substance abuse

"Three children aged 15, 10 and 6 were left behind after the death of both parents. Soon after that, they moved to a little hut near the grave yard where their parents were buried. It is about two miles from here and up in the hill. No one lives there. Some people told the elder sister to come back and stay in the ward. But they said they feel more secure and happy to live in the hut that makes close to their parents. They live in deep poverty. We have market in every five day and then people buy food for five days. They come to the market to buy food only about once in a month. Once I saw her in the rain, wet and shivering. She was heading back to her little hut on the hill. She did not have even an old umbrella." [64]

16 Kachin girl in Namphartkar, Myanmar

"I know a boy whose parents died of AIDS. He is only about 6 or 7 years old. One day I saw a woman said him 'Don't come into our house. If you have your father's disease, you'll pass it on to us!' So the child cried and went away."

10 year old girl in Mawlamyaing

"At school, I have to sit in the last row. The teacher told me to sit there. I don't have any friends at school. The other day, I got 50 kyats. I bought fake meat and gave it to my teacher, but she did not eat it and told me to get lost because I am dirty and smelly."

5 year old infected girl in Theinni

"The relatives promised to adopt all the children. But when they found out that their mother died of AIDS, they broke their promise. They gave the youngest one to strangers because they think he might get the disease too. We don't know where the child is now".

35 year old religious leader in Namphartkar

"The child's mother died a year ago and father died five months ago. He has one elder brother and one younger brother. Now they are staying at the monastery. We did blood tests for them before sending them to the monastery because we know it is a requirement. Even the test results shows negative, the monk did blood testing again. He said for the sake of other kids, he has to make sure they are negative. He will not accept if they are HIV positive."

23 year old social workers in Mawlamyaing

"Usually, we have no problem playing with other kids in the village. Especially the kids from our side are nice. Our grandparents bought us many things to play and we share with other kids. But sometimes when I win the game and I am proud for it, for example we play football and I got many goals, they will try to humiliate me by calling me son of AIDS."

14 year old boy who lost both parents to AIDS and has a younger brother living with HIV

Quotes taken from research report for Myanmar.[66]

Other significant impacts listed by children during consultations included:

- Loss of friends
- Loss of homes and inheritance rights
- Poor health care and poor treatment by health care providers
- Worry about the future
- Lack of love and tender care
- Subjected to bullying
- Social isolation

These lists represent a whole range of serious issues faced by children when HIV/AIDS directly affects their families. The impact of HIV/AIDS on these children covers every aspect of their lives: economic, educational, emotional and social.

The following contains more on some of the above concerns. *Much of what follows comes directly from children who have been interviewed, there is little need for comments from this report writer.*

Experience of stigma and discrimination

Children in Lao PDR were asked: "What will the impact be if you have HIV?" 70% of those aged 11-14 years and 85% of those aged 15-18 years said that their friends will discriminate against them so they would not go to school.[65]

Discrimination against children with HIV or children affected by HIV is frequent.

In Cambodia 10% of children interviewed believe they can be infected if they play with HIV positive children. They say that their mothers tell them not to play with these children. Some children look down on and say bad words to children infected. One teacher says that this behaviour does not come from the children but from their mother.

"My brother has HIV/AIDS, when he was playing with other children the neighbour stopped them"[67]

In Cambodia about a third of children who were affected by HIV/AIDS stated that they experienced discrimination. This makes them feel sad and not good about themselves – one boy told the researchers that he feels ashamed of his parents and wants to run away.

"The neighbours burnt out all the things that my parents had touched in prevention of AIDS when my parents died, and some children scolded me that my parents died of AIDS: I cried tears all night".[68]

13 year old orphan to AIDS in Yunnan, China

A 61 year old grandmother in Bokeo, Laos, is caring for her grand-daughter whose parents have died from AIDS. She does not know the girl's HIV status. "Sometimes she is discriminated against by her friends and has no one to play with."[69]

An interesting comment on discrimination was made by a young NGO worker in Myanmar:

"The people around here will say they don't discriminate, they will say we visit people living with HIV/AIDS. Yes it is half true. They visit them because they are curious and want to know how people with HIV/AIDS look like. Not really because they are sympathetic. They will be very careful not to touch the things in those houses, not to eat or drink anything they offer. And after one visit, they will never visit again." [70]

Not attending school

"My dad was severely diseased and my mom borrowed a lot of money to save him. Being unable to pay my tuition, I left school."[71]
13 year old boy in Xinjiang, China.

Inability to pay for schooling is one of the most common reasons children affected by HIV/AIDS gave for dropping out of school. Many children also drop out because they have to care for their sick parents or work to support their parents and siblings. Often children don't go to school because they have no money for buying lunch or for school books.

Although all children interviewed in Cambodia (many were children affected by HIV/AIDS) said that they attended school, it became apparent that many of these do not attend regularly as they need to earn money or care for sick parents. Some Cambodian children stated that they find it difficult to concentrate during classes as they are thinking about problems in the family. Some children have no energy at school because they need to work at home or outside to support their families.

The researchers in Myanmar found similar situations.

"There are five HIV affected orphans in my village. As it is concerned to me, I waive school fees for them. Even then, they still have difficulties with school book, stationeries and food to bring to school. Two-third of the children could not attend the school for these reasons."[72]

Headmaster in Myanmar

"I am the eldest son. I have a younger brother and a sister. I used to go to school but I stopped going school now. I was not able to go school regularly because I had to take care of my parents when they were sick. After all, I found myself as a very bad student and I decided to stop going school" [73].

14 years old HIV orphan boy from Hpa-an

The daughter of a PLWHA in Savannakhet, Laos said:

"I have concerns about my future if one day my parent dies my younger sister and I...will lose the opportunity of education and have no future." [74]

"I am 11 years old, I live in Phonsaath village in Savannakhet Province, and I am a student at an army school in my village. I am studying in Class 5, my parents got HIV, my father died in 2001 and now my mother is sick. Sometimes I have to be absent from school to take care of her, I need help and support from my friend and other people, I need money for mother's cure and I need my friends to play with me as in the past."[75]

Respondent from Lao PDR

Serious poverty

Many children affected by HIV/AIDS were living in poverty before their parents became sick. This poverty becomes more serious once parents become sick.

As seen in the previous section, children go to work to help their parents. One boy from Xinjiang, China, talked about his family. His father was an injecting drug user and was infected with HIV. His mother sold the house in order to save the father. He now works as a shoe boy.[76]

A 10 year old orphaned boy in Myanmar whose father had died and whose mother was in prison stated:

"We don't have rice for today meals. Food is more important than schooling"[77]

Having to work, caring for parents and families

"I skip school to earn money to support my family and cure my mother" [78]

In the previous section we saw that children often do not go to school as they need to work to support their families or care for sick family members.

An orphaned girl in Indonesia spoke of how she had to balance her time between school and caring for her mother. She was also afraid to talk to the neighbours about her mother's illness because of possible discrimination. She commented that doctors and nurses were reluctant to treat her mother. Once her mother died she needed to work to support the family. [79]

The work children do is poorly paid and menial, it sometimes places them at risk of exploitation. Children reported doing the following types of work: catching fish, selling vegetables and fish, collecting papers and garbage, selling cans, cleaning bottles, washing plates and other domestic work for neighbours, shoe shining.

> *"I clean bottles and sell them to pay for my tuition, however hard I work I could not approach the sum demanded and my teacher let me stand in the classroom being laughed at by my classmates"* [80]
>
> 10 year old girl from Xinjiang, China

> *"The boy is living with his grandparents. His father and uncle died of AIDS. His mother is somewhere else. He uses his spare time to earn extra money for the family and to buy things for himself. He works as a busboy in a restaurant on weekends and after school."* [81]
>
> Comments on a 15 year old boy interviewed during the research in Thailand.

Loss of parents and change of care-giver

Having cared for sick and dying parents many children are then faced with life in another family. Many of the children interviewed have had satisfactory experiences with change of care-givers, however this is often not the case.

Orphaned children normally end up living with relatives, usually grandmothers or aunts. Children in foster families often experience different treatment to that given to other children in the family. Some foster children are not supported to go to school. One boy interviewed in Cambodia used to live with his aunt but always fought with his cousin and is now happier living in a Buddhist pagoda where the monks support him and help him with his studies.

> *"If my mother dies I do not know where to live; now she is sick. I would ask the pagoda or an organization where to live; I do not want to live with my relatives because they are violent."*
>
> *"Now I am staying with my aunt and uncle, they always beat me and my younger sibling. My parents are sick and stay at hospital".*
>
> *"I do not have a good feeling when I am living with my grandparents after my parents died, because my grandfather beats my grandmother almost everyday after he comes back from drinking wine"*
>
> Children quoted in the Cambodia report[82]

> *"The parents died of HIV/AIDS, leaving 2 children behind. The older child is 8 and her sister is 6. The children live with their aunt and grandmother. The aunt has two children of her own. They get to wear shabby clothes, and the food is not the same as the aunt's children. They have to eat rice with cheap vegetables and fish paste when they come back from school. For the aunt's children, the grandmother took out some pieces of meat from the meat-safe and gave them to eat on the sly. I saw it with my own eyes"* [83]
>
> Participant from focus group discussion in Theinni, Myanmar.

> *"A boy had to live in his granny's home because his father was infected with HIV and his mother abandoned him. The incident brought about endless unhappiness to him ...He was victimised both mentally and physically."* [84]

Orphaned siblings are sometimes separated after their parents' deaths.

> *"The relatives take only 3 of 6 siblings. The rest ended up living in other's houses. Those who live with the relatives are slightly lucky. They do not need to work in the farm. The ones in other's houses have to work as slaves."* [85]
>
> 16 year old girl quoted in the research report from Myanmar.

Small numbers of orphaned children are not fostered and end up living alone and on the streets.

"The eldest one was sent to Kuitakai and we don't know about her."

"The child had no house to live in. The creditors came and took possession of the house. So the child was on the streets."

Comments from respondents in Myanmar[86]

The impact of AIDS deaths on carers and children is also significant.

"I am 61 years old and live in Bokeo province (Laos). My son-in-law worked in Thailand, after he came back he married my daughter, he didn't know he had HIV until he was sick and died. Then my daughter started to get sick and she went to the hospital and checked her blood, after that she knew she was HIV positive and then one year later she died. She had one child but I am not sure if she has HIV or not because she didn't check her blood yet. I am afraid that if I die who will take care of her and support her to go to school. Sometimes she is discriminated by her friends and has no one to play with." [87]

Emotional effects of HIV/AIDS on children

Some feelings cannot be mentioned as words

Throughout the research many children commented on the emotional impacts that losing their parents had had or would have on them. Many orphaned children in Cambodia and Myanmar commented on loss of happiness.

"I drew this picture. I am here sitting on the floor. My father is on the chair reading a story to me and my mother brought a cup of lime-juice for him. This is my memories of living in a happy family."

8 year old orphan

"My father passed away. I cannot talk to him and see him anymore. I feel sad, depress and sometimes angry."

14 year old orphaned boy

"My mother was in deep pain before she died. She was very thin because she was not able to eat anything. Since my father died two years before I am the only one who looked after her. I did not want to see my mother's suffering and sometimes I even prayed to God to take her quickly and I feel guilty for such prayers."

17 year old orphaned boy
Quoted in the research report for Myanmar[88]

"I feel jealous when I see a child that has parents, when I see them together, I feel alone."[89]

My family (father, mother, my elder sister and me) go to the beach and take a rest. My sister and I go for swimming. 10 year-old girl in Myanmar, who lost both parents to AIDS and is separated from her sister. She drew the picture in the workshop held with a group of HIV affected children.

Summary of the impacts of HIV/AIDS on children s lives

The impact of HIV/AIDS on children in several Asian countries is acute. Children are suffering extreme poverty and emotional turmoil; they are often exploited or shunned by others. They are not receiving schooling or their schooling is compromised by poor attendance, lack of materials or personal exhaustion. The adult care they receive is inadequate and often they are mistreated by carers. Many are growing up with little hope or happiness and feel ashamed.

Research in Indonesia and Laos revealed that, although children are not experiencing these problems due to HIV/AIDS, there is an expectation that these are problems they might see in the future. Of course, many of the problems exist already due to extreme poverty.

The report from Indonesia comments:

"It was not easy to find children who were confident enough to have positive outlook of their future."[90]

The Cambodian research team worked with children and adults and developed the following list of problems faced by children affected by AIDS.

Money:
- Lack of money in the family
- I cannot earn money
- Only one person earns money in the family
- No money to buy medicine
- Difficult to find a job
- Have a lot of siblings and not enough food
- No money to pay for school

School:
- Do not go regularly
- No study material
- School is so far away, have no bicycle
- Feel not confident to go to school because someone discriminate me
- Fight each other
- Not allowed to go to school

Health:
- Mother got sick
- Member of the family have HIV/AIDS
- Parents have HIV/AIDS
- I seem to always be sick

Family:
- Mother is blind
- My parents died no one to support my family
- No house
- Fighting

Violence:
- Argument with relatives, my aunt hit me
- Angry with my mother
- Father get drunk and fight with the children in the house
- Fighting with the children and not allow them to go to school
- Father lost money when he gambled and fights with my mother and siblings
- Father get drunk and fight with my mother
- Grandmother fight with me
- Cousin fight with me

Personal:
- I feel afraid because member of my family died

C. Children s access to prevention, care and support

Responses to this varied widely. In several countries prevention education was widespread although most researchers reported a significant lack of prevention education in rural areas. Access to care and support was much less widespread. Areas of need expressed at the regional analysis workshop in Bangkok included:

- Prevention education
- Access to condoms and condom promotion
- Provision of prevention of mother to child transmission (PMTCT)
- Voluntary counselling and testing (VCT)
- Availability of anti-retroviral therapy (ART)
- Safe places for children to play
- Shelter / rehabilitation facilities for mothers who are living with HIV/AIDS
- Knowledge of services

During the research many of the questions related to care and support services could not always be answered by children and this was a topic area where adult responses were important. However children had a lot to say about prevention education and some had knowledge related to the other areas of questioning.

Knowledge of available services

It is important to note that in many instances services are available however they are not always well publicised or understood. Often available services were reported to be unfriendly to children and youth.

Access to prevention of HIV

HIV information and prevention education.

In Cambodia there have been extensive AIDS awareness campaigns. Most children interviewed had basic knowledge which they said they had gained from a variety of sources including media, NGOs, school, government officials and at community gatherings. Children stated that those who did not know about HIV/AIDS included street children, small children, those who do not go to school, those without access to public meetings because their parents do not allow them, because they are busy working or because of long distances; also included were rich children.[91]

The research report from Indonesia states that HIV/AIDS services are poor except for Jakarta. Most prevention activities are one-off campaigns directed at particular groups perceived to be at high risk of HIV infection.[92]

In Laos at least 70% of children over 11 years of age had learnt about HIV/AIDS from media, school or parents. However, 80% of children in the age group 8-10 years had never heard of HIV/AIDS. The report comments that "many people especially those who live in remote areas don't know and don't understand about HIV/AIDS and how it is transmitted, how to prevent it and how to take care of themselves if they are HIV positive."[93] Of adults living in remote areas only 40% had knowledge of government prevention policies.

In Myanmar prevention services are there, usually provided by NGOs, but they generally only reach urban children.[94] Isolation is not the only reason children don't hear about HIV prevention.

"At the workshops and discussions, there are more girls than boys. And it is for sure that not every child is there. Some have to work for earning or to help their family. Some are too shy to join the discussion. Some are unable to read and write, so they dare not participate. The educational activities do not reach all the children concerned."[95]

17 year old boy from Mawlamyaing, Myanmar.

Children waiting, Laos

Despite the Thai government's emphasis on HIV education, learning was limited in the areas subject to the research. This was primarily because cultural factors restrict education: "Children are shy to talk about sex and ...teachers do not want to speak too explicitly".[96] Children are embarrassed to ask for information because they are afraid adults will think badly of them.

In all countries there are prevention services to which some children have access. These information services are generally provided by government (including schools), NGOs and the media; there is some information provision by religious leaders. However, many *children at significant risk of HIV infection such as street children, working children or children who migrate, do not have access to prevention education.*

Availability of condoms

An Indonesian delegate to the December analysis meeting said that it was very difficult to talk about condoms in his region. Children understand that condoms can prevent the spread of HIV but it is not at all clear how specific that understanding is or how widely available condoms are. In Thailand where condom use has been vigorously promoted for a number of years "the procedure for taking condoms is often not children and youth friendly".[97]

Prevention of Mother to Child Transmission (PMTCT)

In Cambodia mother to child transmission is a major concern among children and adults.[98] There are some services but they are few and often PMTCT is not well publicised. The December workshop in Bangkok heard from researchers that all countries had some PMTCT services but there was often little awareness of them.

PMTCT is one strategy which clearly reduces the impact of HIV/AIDS on children. Not only does PMTCT mean that fewer children are born with HIV, it means that families where there is already HIV do not have the added stress of caring for an HIV+ child. Of course, PMTCT should be allied to ART to ensure that HIV+ mothers are well enough to care for newly born children.

In Indonesia PMTCT services were available in only one of the five research sites.

The Myanmar research found that most people had never heard of PMTCT and such services only occur in main townships.[99]

In Xinjiang besides strengthening prevention education, PMTCT services were being developed.[100]

The Thai PMTCT programme allows some migrant women to join in, even though migrant people are not permitted access to the national low cost health services.[101]

Access to care and support

One positive response in the research often came when children were asked where they could find care or support. A number of children in several countries referred to friends, relatives and community support. This informal support was spoken about in many countries.

In Yunnan, China, orphaned children were being supported to stay in school and provided with basic living expenses through a government and UNICEF initiative.[103] The reports from China have many examples of children stating that they want others to be helped.

In Thailand care and support is often the responsibility of relatives "because society values family members helping each other out".[104] The Life Home Project supports HIV positive mothers by providing training and assistance to start businesses.[105]

In Myanmar whilst there exists a tradition of support for children coming from relatives, deep generalised poverty means "most people are not able to extend their hands to those who are in need".

Support for children affected by HIV/AIDS in Cambodia:

The majority of the children say that if they have problems they will talk to their friends and to their mother, some children say they will talk to their grandmother or neighbours. In the community children say that people who are infected by HIV/AIDS like to talk to other people that are infected by HIV/AIDS and they help each other, they also mention that adults talk to the monks. Expressed from the children is receiving support from the monk and the organisation. From the monk they get food such as rice and also material for studying. The monk gives advice to the parent and they are a linkage between the families and the organisation. Overall the respondents say that if they have other problems they want to talk about they turn to friends and neighbours.

"...When my friend is sick I go to her house and help her cook food such as rice"

"..The monk gives me encouragement and hope"

The children say that they believe the hospitals are good and that they have been treated well when they visit the hospitals. However the hospitals are often far from their house and children especially from the rural sites say it is difficult to get there. A small number mention they were not treated fine because they had no money. If someone in the family is sick the children say they take care of them. They cook rice and go out to find medicine. If they need much medicine they first try to earn more money. If they need help they ask their neighbours.

Taken from the research report for Cambodia [102]

"Very few community based organizations and some non government organizations are providing supports to those children but it is obvious that they were not able to reach all. Community home based care activities by Myanmar Nurses Association are available in some sites of the research but it is still limited and not really focuses on the needs of children yet."[106]

"I can't do anything except say words of sympathy. So do the other people. We are poor and every one lives in similar situation. The only difference is that these affected children have no parents. There's no counselling services or in-cash assistance from outside. At least I haven't heard of any."[107]

15 year old boy living with both parents in a Shan village, Myanmar.

At community level there are some people who have formed groups to support others:

"We formed a group ourselves, who have same faith and same attitude. We help vulnerable children and orphans of all kinds. I myself have 6 orphan children in my house. I help as much as I can afford. I myself am not a rich man, so we have difficult times. But I send them to school and feed them the food I have. We see what kind of physical and mental suffering these children are going through, how downhearted they are feeling."[108]

A 45 year old man in Myanmar, who has been looking after six orphaned children.

With the exception of China there is little government help for children except for orphanages. There is generally little official assistance for children to stay in their communities or to support foster parents. However NGOs provide some support in Cambodia and Myanmar.

In Cambodia Save the Children has been successful at organising support for children to go to school through some Buddhist pagodas. In China in Fuyang (not a site for this research) Save the Children implements a project for orphans in partnership with the Women's Federation.

Home-based care

Access to home-based care is something which can reduce the impact of HIV/AIDS on children, especially those who are carers. However there was little data written up about this, but it was acknowledged as an issue at the December data analysis meeting.

Access to Voluntary Counselling and Testing (VCT) and Anti-retroviral Therapy (ART)

Access to voluntary counselling and testing (VCT) services and particularly to anti-retroviral therapy (ART) are important in that such access by adults may affect children's futures. If HIV positive parents have access to ART then there is a prospect for them to live much longer; this means that children affected by HIV in their families may not have to deal with sickness and death.

Survey questions about access to ART and VCT were not asked in all countries.

In Indonesia there was some availability of ARV but access to providers was often difficult due to distance and cost of travel. VCT services are available in four sites but again travel is a problem.[109]

In Myanmar there are some services but only one state among the three selected for research had ART available. There is the obstacle of travel expenses to the treatment site. 85% of respondents had never heard of VCT and many said that they would not use such a service - they did not want to know their HIV status, they feared lack of confidentiality.[110]

There is increasing access to ARV and VCT in Cambodia and generally good access in Thailand.

Discussions about mitigating the impacts of HIV/AIDS on children need to include access to ARV and VCT services by PLWHA who are parents; access to PMTCT should also be considered.

Summary of children s access to HIV prevention, care, and support

In every country there is some access to services related to prevention, care and support. All countries have methods of providing HIV/AIDS messages and conduct prevention activities and campaigns. The accessibility of these and their appropriateness for children differs. Availability of condoms and discussions of their use are complicated by cultural attitudes and adults' and children's reluctance to talk about sexual activity.

Some of the children most at risk of HIV infection such as street children and those who migrate for work are the very children often not reached by prevention education activities.

Access to care and support services is not widespread. The most significant and immediate care and support which children receive comes from their own communities. In many of the countries there are traditions of family and community care. Such systems need to be acknowledged and encouraged as they form the basis of what one report calls "social care". Care and support is also provided by some NGOs, government, schools and religious institutions.

"Some are unable to read and write so they dare not participate"

Access to care, support and prevention does not simply mean the availability or existence of these services. Access needs to take into account the following:

- Appropriateness, including language, clarity and interest
- Children's literacy
- Adult attitudes
- Children's embarrassment
- Distances to be travelled
- Children's availability - are they working, caring for parents, siblings?
- Promotion of the services

Clinical services for adults

Availability of services for adults and their use by adults can reduce the impacts of HIV/AIDS on children.

Other findings

During the research there emerged a number of other issues not necessarily related to HIV/AIDS, but which concerned children deeply. These are briefly discussed here; some may be co-factors in increasing the impacts of HIV/AIDS on children.

Violence against children and verbal abuse of children

At least four countries found that some children were experiencing violence and abuse. Some of the examples are mentioned above and significant numbers of children reported beatings and abuse from parents, relatives, teachers, older children and gangs. Violence against street children seems to occur frequently.

Verbal abuse of children, especially by teachers and fostering relatives, is frequently mentioned.

Domestic violence

Domestic violence was also a common topic of concern for children. Whilst this did not necessarily mean that they themselves were subject to physical or verbal abuse, the impacts of family fighting were of considerable concern.

Family separation

Divorce or family separation was another concern. The effects of these on children's emotional, economic and social lives are considerable.

Access to education

Access to education and loss of access or fear of loss of access were some of the most frequently discussed matters. Whilst loss of education was talked about primarily as a result of being affected by HIV/AIDS, it is very clear that access to education is a major concern for children in all the involved countries.

Lack of education is the result of many factors for these children:

- Cost of paying for teaching
- Cost of educational materials and uniforms
- Cost of lunch
- Discrimination by other children and teachers because of poverty, disability, illness, parental reputations
- Distance needing to be travelled to attend school
- Having to work to help the family (either at home or elsewhere)
- Parental unwillingness to send children to schools

Effects of drug abuse on families

Family poverty and disintegration because of drug use and alcohol abuse are also concerns for children.

In summary

This brief section covers a number of major concerns expressed by children during the course of the research. These concerns are not always related directly to HIV/AIDS but the matters referred to directly impact on children's lives and their self-esteem. *Violence, verbal abuse, domestic discord and poor or no education all make children more vulnerable in society by undermining their self-confidence and ability to make decisions.* These are some of the factors creating feelings of hopelessness among children.

On a very positive note

Many children interviewed in all countries expressed concern for others less fortunate than they. There were frequent comments related to actually helping others, wanting to help others or to making those in authority assist. Most children interviewed were themselves in difficult circumstances but many were worried about those in more difficult circumstances.

There were also many adults interviewed who expressed a desire to help even though they themselves often lived in considerable poverty.

CHAPTER FOUR : CONCLUSIONS

Conclusions

Individual country reports all contained conclusions related to the issues of most importance for that country. They are quoted here. (There has been some minor editing and re-writing of these conclusions).

CAMBODIA

The emotional burden on the children is enormous, watching their parents getting sicker and sometimes being the ones responsible to take care of them.

- A major factor that puts children at risk of HIV/AIDS, acknowledged by both adults and children is mother to child transmission through childbirth or breastfeeding. This is expressed both from the children and adults as the biggest risk for a child to get infected by HIV/AIDS.

- A common scenario described by the children is migration. The father leaves the community to look for work elsewhere. He gets infected by HIV/AIDS through sexual contact with no condom use. The disease is later transmitted to the mother, who later passes on the disease through childbirth or breast feeding.

- Children are at risk of HIV/AIDS infection when they are involved in "risky behaviour" such as having sex without a condom and drug use. The children mention that orphans and street children are more vulnerable because they have no adult support and advice and nobody encourages them to go to school.

- Children have knowledge about HIV/AIDS but there are many misconceptions. One third of the respondents believed that HIV/AIDS can be transmitted from mosquitoes. One tenth believe that you can get the disease while playing or holding hands with someone infected. The children say that the major source of information about HIV/AIDS comes from their neighbours, caregivers or other adults in the community. Adults in particular in rural communities express issues about difficulties in reaching information meetings about HIV/AIDS held by organisations because they are held at a site far from the house but also because they themselves are busy with work or taking care of the household.

- Children need more emotional support. They face many difficulties living in families affected by HIV/AIDS. Due to lack of money the children's living standards are poor and they need to earn money for the household especially when their parents are sick and cannot work anymore. The emotional burden on the children is enormous watching their parents getting sicker and sometimes being the ones responsible to take care of them. If children know their parents have HIV/AIDS they also know they will die and they worry about what will happen to them and where will they live? In particular if the parents sold their assets and the children no longer have the house. Some children do not want to live with their relatives as they believe they will be subjected to violence.

- All of the respondents are in school although in particular older girls do not go regularly as they need to help out in the household. There are many responsibilities for the children in the family such as helping to earn money for the household, helping with farming, housework and looking after younger siblings. The children have little free time as they do double work, going to school and helping out in their families.

- Although the children mention there is less discrimination than before due to higher

awareness of transmission and prevention of HIV/AIDS they still sometimes see examples of discrimination in their communities such as mothers not allowing their children to play with a child infected by HIV/AIDS.

- Children whose parents have passed away are facing many problems. Many have a lack of assets as things have been sold to pay for medical care and funerals. Sometimes the parents also left them with debts. Foster children are not treated the same as biological children but are expected to do more work in the household and sometimes are not allowed to go to school to the same extent.

CHINA

These conclusions are drawn from a summary of the reports from Xinjiang and Yunnan.

- Children in both research sites shared concerns about family health and loss of parents linked to HIV/AIDS.

- HIV/AIDS is seen as leading to poverty, a significant consequence of this is lack of schooling.

- Health of family and access to schooling are interrelated.

- Children are aware of the link between education and employment.

- Children experienced the impact of discrimination due to HIV/AIDS. Friendship, self esteem and dignity are affected by discrimination.

- Children worry about lack of self confidence and mental agony resulting from discrimination.

- Children are concerned about the attitudes of adults (especially parents and teachers) to them and the impact this has on them.

- Children are concerned by lack of parental care due to loss of parents, drug abuse and divorce.

INDONESIA

- The participatory process of the research has shown how children with particular characteristics in Jakarta, Pemangkat, Ambon, Kupang, and Belu are vulnerable to HIV/AIDS.

- A “marriage” of poverty with other factors such as lack of adequate support for children, low level of education and knowledge on HIV/AIDS and reproductive health among children and adults causes children to be vulnerable to HIV/AIDS.

- Risk behaviours related to substance abuse, sex work and unsafe sex put children in a more vulnerable position to HIV infection.

- Children infected with and affected by HIV/AIDS have to struggle with many problems, such as overcoming stigma and discrimination, survival needs, taking care of parents or their own child who also has HIV.

- Many of these children seemed to be overlooked by all caregivers, especially from the government.

- There have been several initiatives for children implemented by NGOs.

- Government responses to reduce the vulnerability seemed to be far from what are needed based on children’s rights.

Family living in rural Laos.

LAO PDR

- Main factors and problems that made children and young people more at risk of being infected with HIV were poverty, gender imbalance, migration, lack of access to information and basic services.

- More than half of the population is poor; most of them are farmers and live in rural areas. They cannot access basic information about HIV/AIDS. The services cannot cover all rural areas.

- After the harvest season most of the children in rural areas migrate to the city and abroad to earn money; this might bring them to be more at risk of HIV infection.

- Expanding communication networks, infrastructure and development in the city creates a need for labour. There is an increase in migration to towns, including the migration of children. Without adequate information and education before migration, there is increased vulnerability to infection with HIV.

- Lack of understanding of HIV/AIDS may lead to transmission to spouses and later to newly born children.

- Most of the women cannot negotiate how to say no to sex.

- Parents with HIV will impact both directly and indirectly on the family and community.

- Directly, newly born children may get infected with HIV from their mother. Their vulnerability is related to problems with their health and accessing care and support. They will also lack opportunities for education and possibly will not attend school. When parents die, it may be hard to find someone who will take care of them and support them.

- Indirectly, the children may not be HIV+ but they may not understand properly about PLWHA who live around them, because the provision of information about HIV/AIDS in some areas is limited. This may result in discrimination.

- There is only one care centre for PLWHA in Laos - in Savannakhet province. Access is difficult and costs of travelling to and living in Savannakhet are high.

- PLWHA worry about children dropping out of school because of lack of money, having to care for sick parents and discrimination by other community members.

- Children worry about what will happen to them if their parents die and they have not had an education.

MYANMAR

> *"The education programmes are good. I like them. I learn more about the disease and have a chance to participate in discussions. You can take care of yourself in everyday living. So I feel satisfied. However, children in the countryside wouldn't know very well. Children in villages would be worse. Transportation is difficult too, so they don't get knowledge. The educational activities and discussions do not reach all the children concerned."*[111]
>
> 14 year old boy from Hpa-an.

- Poverty is the most connecting cause to the risks of getting infected; poverty is linked to engaging in sex work, illegal migration, early sex and early marriage, lack of proper knowledge on HIV/AIDS and condom accessibility.

- Northern Shan state is considerably engulfed with the injecting drug problem. Respondents said 70% of men are drug addicts in their community and boys as young as 14 usually start using drugs.

- Cross border migration to neighbouring countries, especially migration of young children poses a key risk factor in Karen and Mon States.

- Low level of positive behavioural change towards sexual activity is found although necessary information on HIV/AIDS and condoms is provided.

- Impacts of HIV/AIDS on children's lives include economic problem (poverty), psychological distress, discrimination, exploitation and death of young children.

- Poverty plays a key role in determining the degree of negative impacts on children and results in food insecurity, school drop out, poor health, family disintegration and the risk of being infected with HIV.

- Conservative social values about sexuality combine with lack of proper knowledge on HIV and AIDS to stigmatise people living with HIV/AIDS.

- Despite the fact that HIV/AIDS is continuing to spread, prevention, and care and support services in Myanmar are almost non-existent.

- Access to ARVs needs a lot to be improved as it is critical as it prolongs the life of infected parents and delays children becoming orphans.

THAILAND

- Migrant children do not have the opportunity for education, and therefore have little access to information about HIV/AIDS.

- Although the Thai students receive basic information about HIV/AIDS in Grade 9, the curriculum is short and leaves out many crucial aspects about HIV/AIDS education such as life skills, anti stigma and discrimination, increased awareness.

- Out of school youth do not have access to HIV information because school is the main channel where information is transferred.

- Youth do not know about the services and do not think services are youth friendly. Thailand offers many types of services that are more accessible to the people but youth do not know about them, for example voluntary counselling and testing, ART program, PLWHA support network.

- Unprotected sex is common, either because the children and youth are not aware of the danger of HIV/AIDS or they still do not have a good attitude about condom use. Peer pressure, media influence and social trends also add to the pressure that drives sexual risk behaviours among children and youth.

- The gap between children and trusted adults who can advise them seems to be increasing.

- Financial difficulties in HIV/AIDS affected households can lead to many things, such as risk of discontinuation of education for children and deteriorating health due to malnutrition.

- Stigma and discrimination against people living with HIV is one of the most crucial problems found in this research, which makes it difficult for the PLWHA to live in the society.

- Many caregivers face financial and emotional problems, which causes the quality of care for children to be low.

OVERALL CONCLUSIONS

The above conclusions have been reached by country research teams and children after several months of in-depth investigations. They represent the views of children on how HIV/AIDS can and does affect them. Different countries have different issues which are of most importance. However, the overall picture is that in many of the research sites HIV/AIDS is having significant impacts on children's lives, either directly or indirectly; these impacts are not isolated to children living in areas of advanced HIV epidemics.

Child researchers in both Xinjiang and Yunnan, China, ranked concerns about HIV/AIDS in the "top three" of all the concerns of children.

What emerges from this research is a picture of an epidemic which has profound implications for the future of children and the provision of services for children.

Conclusions of the regional research:

Factors that place children at increased risk of HIV infection

- ➢ Prevention education and availability of information is inadequate. Whilst all countries have HIV/AIDS prevention education activities, these are not reaching significant numbers of children. Children's knowledge and awareness of HIV/AIDS is inadequate because information, even when available, has not been designed specifically for children's groups and is often not accessible.

- ➢ Adult awareness is not adequate especially in rural areas. In addition, because of ignorance and cultural beliefs, some adults do not allow children to have access to information.

- ➢ Both children and adults often believe that HIV/AIDS awareness is not relevant to them.

- ➢ Children's access to condoms is limited and discussion of condom use is a controversial matter in many societies.

- ➢ Children and young people have not widely adopted condom use.

- Whilst programmes promoting and providing prevention of mother to child transmission exist they are usually poorly understood and often difficult to access.

- Children are being exploited and trafficked for sex by parents and other adults.

- Migration both within country and across borders increases the vulnerability of children to HIV infection and is a major co-factor in the exploitation of children for sex.

- Children living on the streets are at significantly increased risk of HIV infection and of exploitation and violence.

- Both children and adults identify the lack of adequate adult care as a factor which places children at increased risk of HIV infection.

Impacts of HIV/AIDS on children's lives

- Children's education is being undermined by an inability to participate in formal classes due to living in families affected by HIV/AIDS.

- Children are working to support sick parents and younger siblings.

- Children are performing the tasks of carers for sick family members.

- Children's futures are being compromised because of loss of family property and income caused by parental illness and health expenses.

- Children affected by HIV/AIDS are suffering discrimination and rejection in numerous communities.

- There are serious emotional and psychological impacts on children affected by HIV/AIDS. These include: grief at parents' declining health and death, loss of self esteem because of increased poverty and discrimination, loss of friends, loss of hope due to lack of education and of adequate adult support.

- Care of orphans and fostering arrangements are often inadequate. In very poor communities, general economic and social need affects the lives of orphans in particular. There is considerable evidence of the exploitation and maltreatment of orphans by fosterers, adults and other children.

Children's access to prevention, care and support services

Poor access to some services is often a factor which increases children's risk of infection and vulnerability. Some conclusions in this section are similar to conclusions in the previous two sections.

- Some HIV/AIDS prevention activities are especially designed for children. However, access to these can be limited by lack of transport, adult disinterest and children's other obligations (to work, clean the house etc).

- Prevention education is often inappropriate for children; language is too complex and information lacks clarity, especially related to transmission of HIV.

- Children who are illiterate or with poor literacy are generally not reached by prevention campaigns. They are being denied essential knowledge.

- Health and information services are usually designed for adults; children often find them to be unfriendly.

- Care and support services for children directly affected by HIV/AIDS are generally poor or non-existent.

- ➢ Children are finding support within their own communities from other children, from relatives, from local leaders like Buddhist monks and from "kindly" adults.

- ➢ Fostering systems for orphans are poorly supervised; there seem to be few mechanisms to address exploitative fostering by relatives.

The following conclusions, whilst not directly about HIV/AIDS, are related to significant matters for working with children.

Children's participation and child-led research

- The involvement of large numbers of children as respondents in this research has yielded good results. Many children have expressed clear opinions about their own situations and the situation of others. Importantly the information and opinions expressed by children have not differed markedly from those expressed by adults. When researching about children it is important to research among children.

- Child-led research was a successful strategy in Cambodia and China. Child-led research has been a powerful means of empowering a small number of children, increasing their confidence and skills. Child-led research has been a successful strategy in changing the opinions of some adults about the capabilities of children.

- Child-led research has demonstrated to many other children what children can do.

- Child-led research needs a lot of preparation time for the researchers, children participating in the research, associated adults and the community.

Other conclusions

- Violence towards children is a serious issue in most countries. This violence occurs in homes, schools and on the street.

- Education is seen by children as a key factor in their lives. Many of the concerns of children relate to a fear of lack of education.

- Children show a significant concern for the welfare of other children; some offer practical help but most hope for a better future for children in greater difficulties than themselves.

- There are some successful projects at community level attempting to address the impacts of HIV/AIDS on children. These include work with Buddhist monks in Cambodia and development of community help systems as seen in Myanmar. Such initiatives should be encouraged.

CHAPTER FIVE : RECOMMENDATIONS

It is inevitable that an extensive research experience will result in a number of recommendations. These recommendations are relevant to all stakeholders. **Communities, donors, governments, NGOs and UN bodies** need to identify how they can best contribute to reducing the impact of HIV/AIDS on children.

There is one over-riding recommendation:

With the HIV/AIDS epidemic spreading and increasing its impact in the Asia region, communities, donors, governments, non-government organisations and UN organisations must increase their funding and programming for children affected by HIV/AIDS.

Specific recommendations are:

A. Reducing children s risk of HIV infection

Prevention education

- Develop life skills programmes for children on reproductive health and HIV/AIDS transmission and prevention.
- Develop life skills programmes for children related to self-esteem, child protection and children's rights.
- Develop information, educational materials and communication strategies which are appropriate for children, child-friendly and clear in meaning.
- Develop strategies to reach children who experience difficulties of access to education and information, including: children with low literacy, migrant children, out-of-school children, rural children and street children.
- Improve the accessibility of condoms for children and their understanding and acceptance of condom use.
- Mainstream HIV/AIDS education into government and NGO health promotion programmes and into all Save the Children programming.
- Integrate HIV/AIDS and sexual health into basic formal education programmes.

Clinical and health services

- Increase the availability and accessibility of prevention of mother to child transmission (PMTCT) services, anti-retroviral therapy (ART) and voluntary counselling and testing (VCT).
- Address the issue of inadequate health care services in poor and remote areas through increased financial support, more hospitals and health centres, training of medical staff.

B. Mitigating the impact of HIV/AIDS on the lives of affected children

- Provide services to ensure that all children have access to sufficient food, shelter, clothing, education and health care.
- Develop services which provide psycho-social support to children affected directly by HIV/AIDS, including child clubs and activity centres.
- Develop and implement systems to ensure the appropriate fostering of orphaned children, including provision of support for caregivers and monitoring the quality of care.

- Develop and implement systems to monitor the care of vulnerable children.
- Increase the number and scope of vocational training projects for children.
- Develop and implement programmes which address discrimination and stigmatisation related to HIV/AIDS.
- Develop programmes which address stigma and discrimination related to children living on the street, children with disabilities, children who are orphaned, migrant children and children living in families where there exists abuse of alcohol and drugs and domestic violence.
- Develop child protection mechanisms and activities to address the abuse and exploitation of children and to prevent child sex work and child trafficking.
- Develop and implement legal frameworks to protect children's rights, including property rights.
- Improve systems for collecting statistics and data about numbers of orphans and develop early notification systems related to children directly affected by HIV/AIDS.

C. Children s participation

- Implement and increase programming that involves children in meaningful participatory processes and activities.
- Ensure that children are recognised as important in all HIV/AIDS programming and that the voices of children in this epidemic continue to be heard.

D. Advocacy

- Document existing successful project models and adapt such models for wider use.
- Conduct media campaigns to raise awareness of the many issues facing children affected by HIV/AIDS.

Migrant Children Workshop, Thailand.

- Conduct activities which increase adult awareness, especially among parents and community leaders, of the need for children to receive HIV/AIDS information and education.

- Improve the collaboration between organisations working on issues related to the impacts of HIV/AIDS on children and increase commitment to joint programme development and mutual support.

Save the Children should continue to address some of the above through a continuing regional programming initiative and through increased activity in specific countries.

Summary of recommendations

The above recommendations may be summarised as follows:

- Develop and implement HIV information and education programmes specifically designed for children, emphasising clarity of messages and ease of understanding. Ensure that such programmes are widely available, especially to the following: street children, rural children, working children, out-of-school children, children who migrate and children living without adequate adult care.

- Develop and implement comprehensive programmes for children directly affected by HIV/AIDS, especially orphans and children who are carers. Such programmes need to ensure that children have access to sufficient and nutritious food, clothing, shelter, education and health care.

- Develop and monitor adequate fostering policies and arrangements, particularly to ensure proper adult care and an end to exploitation of foster children.

- Continue and increase programmes related to child protection, children's rights and to ending child trafficking and exploitation.

- Continue and increase anti-discrimination activities.

- Develop and implement life skills activities for children, recognising the special need for these skills in a world with HIV/AIDS.

- Continue and improve clinical services to PLWHA, especially those who are parents, particularly the following: availability of anti-retroviral therapy (ART), prevention of mother to child transmission (PMTCT) and voluntary counselling and testing (VCT).

- Continue and increase the active involvement of children in HIV/AIDS activities and other activities which impact on their lives.

- Recognise and address the impacts of HIV/AIDS on children in all HIV/AIDS programming.

- *Save the Children should continue to address some of the above through a continuing regional programming initiative and through increased activity in specific countries.*

Final comment:

The eager and willing participation of children in this research and the wisdom shown by many of them have been inspirations to many adults and other children.

Children want to learn and be happy, it depends on adults to realise their dreams

NOTES

[1] *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* - UNAIDS and UNICEF. (July 2004) (Framework)
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[3] UNAIDS Uniting the world against AIDS. Country Profiles.
[4] Reference group on HIV/AIDS Surveillence (2005)
[5] Research Report for Cambodia (Cambodia) p 5
[6] Research Report for Thailand (Thailand) p 37
[7] Cambodia p 7
[8] Cambodia p10-11
[9] Research report from Yunnan, China (China(Y)) p9
[10] Thailand p7
[11] Research Report from Indonesia (Indonesia) p 13
[12] Indonesia p14
[13] Cambodia p14
[14] China (Y)p9
[15] Research report from Xinjiang, China (China-X) p10
[16] Cambodia p16
[17] Cambodia p16
[18] China Xinjiang p17
[19] Research Report from Myanmar (Myanmar) p19
[20] Myanmar p19
[21] Myanmar p19
[22] Myanmar p19-20
[23] Myanmar p20
[24] Cambodia p17
[25] Indonesia p27
[26] Thailand p10
[27] Cambodia p17
[28] Mynamar p18
[29] Myanmar p18
[30] Myanmar p10
[31] Indonesia p23
[32] Cambodia p17
[33] China (X) pp13,15,17, China (Y) pp12-13
[34] Indonesia pp15,18,20,22
[35] Myanmar p8,10
[36] Thailand p16[37] See Indonesia pp17,18,20
[38] Myanmar p11
[39] Cambodia p19
[40] Indonesia p18,21
[41] Myanmar p12
[42] Myanmar p14
[43] Thailand p11
[44] Thailand p16
[45] Cambodia p18
[46] China (X) p14-15
[47] China (Y) p13, Myanmar p13
[48] Indonesia p21
[49] Mentioned in context of children living near brothel areas (Indonesia p21)
[50] Myanmar p21
[51] Myanmar p21
[52] Thailand p12
[53] Research report from Laos (Laos) p20
[54] Laos p20
[55] Cambodia p19
[56] Myanmar pp14-15
[57] China (Y) pp12,15, China (X) pp16,17,19
[58] Indonesia pp15,21
[59] Thailand p13
[60] Cambodia p19
[61] Myanmar p31
[62] China (X) p20,21
[63] Indonesia p21
[64] Myanmar p34
[65] Laos p21
[66] Myanmar pp27-29
[67] Cambodia p23
[68] China (Y) p17
[69] Laos p22
[70] Myanmar p29
[71] China (X) p19
[72] Myanmar p26
[73] Myanmar p26
[74] Laos p24
[75] Laos p27
[76] China (X) p18
[77] Mynamar p26
[78] Cambodia p22
[79] Indonesia p29
[80] China(X) p18
[81] Thailand p21
[82] Cambodia p23
[83] Myanmar p32
[84] China (Y) p17
[85] Myanmar p33
[86] Myanmar p33
[87] Laos p22
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[89] Cambodia p24
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[93] Laos p24
[94] Myanmar p5
[95] Myanmar p35
[96] Thailand p25
[97] Thailand p28
[98] Cambodia p30
[99] Myanmar p36
[100] China(X) p24
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[108] Myanmar p39
[109] Indonesia pp32-33
[110] Myanmar pp37-38
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ANNEX

ANNEX 1: SUMMARY OF INTENTIONS

Our research project seeks to explore:

- the factors that place children at risk of HIV/AIDS infection,
- the impacts of HIV on children's lives,
- children's access to prevention, care, and support services.

The research seeks to achieve a high degree of participation from children.

The research is action-oriented - we aim for there to be action for changes during the research and that the research will bring about advocacy and action for change.

The research aims to bring about changes in the following:

- the lives of children and young people,
- policies and practice affecting children and young people's lives,
- children's and young people's participation and active citizenship,
- equity and non-discrimination of children and young people ,
- civil societies' and communities' capacity to support children's rights.

We aim to initiate changes in these areas during the research and as a result of the research.

As our research is participatory we will use a mix of methodologies, trying to achieve high levels of children's participation, our approaches will include: children's workshops, child-led research, small group discussion, in-depth interviews.

Consultation of our main target group is essential and we will report back to our respondents.

Our research also involves the active participation of various adults who are significant in children's lives, including parents (especially people living with HIV/AIDS), carers of orphaned children, local community and religious leaders and government officials.

Our research will be carried out with respect for the confidentiality and well-being of the respondents.

During the research process we will consult with each other, both in-country and with colleagues in other countries.

ANNEX 2: UNDERLYING PRINCIPLES FOR RESEARCH

All researchers have an obligation to adopt an ethical approach to their work. Academic researchers usually are supervised by an ethics committee. In undertaking research with children we need to adhere to these principles.

Consent

Researchers should obtain informed consent. This means that you need to explain what research and interviews will be about and how the research will be used.

Ensure that all respondents are completely happy to be interviewed or be part of a research process. Especially with children they may have been selected by an adult and told to participate. Younger children may not be very interested in the research process or understand what it is - encourage their participation by talking about the methods.

Confidentiality

There must be respect for people's confidentiality at all times especially of things said in individual interviews. Assure people you are interviewing that what they say will not be attributed to them in person, although if it is very important it may be quoted. When working in groups ask all the members to respect the confidentiality of the other group members.

Some ethics for the researcher

Researchers have a clear obligation to protect the interests and well-being of those we study; we need to protect their rights and privacy. You need to ensure that participation in research will not result in any harm (this is sometimes difficult to assess).

Researchers should try to avoid unnecessary intrusion on respondent's privacy - in this particular project this could be difficult. Try to allow people to speak for themselves rather than probing too far - this requires great sensitivity. If someone reveals some deeply personal secret, it is probably important to talk about it and assure the person about confidentiality.

Research often raises people's expectations. One of the hardest things for researchers to tell people is that this research, whilst it may lead to some change, is no guarantee that change will happen. I think in committing ourselves to this research project we should also be committing ourselves to the principle of working for change. But we cannot promise anything.

Children are relatively powerless so researchers need to take a particular responsibility for their protection. This may involve talking to adults beforehand and getting their agreement that they will not ask children: "What happened in that interview?" etc. If you discover incidences of child abuse during your research, talk about it with the other researchers and the research manager - remember we are Save the Children and we have absolutely clear obligations to do our best to live up to the organisation's name!

Reporting back

Once the results of information gathering have been compiled it is important to report back to your respondents. It is usually not possible to report back to all those who have been involved but you must try to report back to at least a majority of them. Reporting back can be very dull - most of your respondents do not want to read or listen to long lists of statistics etc. Try to make your local report back sessions interesting.

The framework suggests that you conduct the research in two steps; this would make reporting back easier as a report back on issues and problems raised will naturally lead to a discussion of what people suggest can be done to change the situation.

Incentives

There will be different views on this. Some people say that offering incentives is unethical in any circumstances; others argue that it is unethical not to offer incentives.

Incentives can take many forms and paying respondents travel costs for participation in research is in my view not an incentive - if we pay the researchers' travel costs why don't we pay those who are the "subjects" of the research? Without them there would be no research!

You need to decide before hand what the policy is going to be and it should be consistent and fairly applied.