a strange illness

issues and research by children affected by HIV/AIDS in central China

Fuyang Women's and Children's Working Committee

Save the Children

a strange illness

issues and research by children affected by HIV/AIDS in central China

> '*Children publicly call it a blood selling strange disease or illness. When you get to know them well they will tell you it is AIDS. One boy wrote HIV/AIDS on his hand and showed it to us discretely, only because of his worry about discrimination and stigma. Children know that when people know a family member is infected with HIV, the whole family is affected, and that they cannot find a job in the future and no one will want to marry them.*'

Fuyang Women's and Children's Working Committee

Save the Children

COVER PHOTOGRAPH

'Wang Na Na at her grandma's house. People said that her parents died. She lives with her grandma.'

'There is a strange, horrific, illness.'

'My mother had a strange illness because she sold her blood, and then she died some months later.'

Contents

SUMMARY

'A Strange Illness…' is a report of issues and concerns raised by orphans and children affected by HIV/AIDS in an area of central China with a severe HIV/AIDS epidemic. This project was undertaken as a preliminary study for a longer programme of child-focussed work in the area to provide care, support and treatment within a framework of child protection and children's participation.

The epidemic was caused through blood-selling by poorer adults and the bad practices used by entrepreneurs in returning some mixed blood of several people to sellers. Large numbers of adults have died, many are dying and many are infected. Some children are also infected. Children are being orphaned. Many children are experiencing the severity of this impact emotionally and physically, yet have received only sporadic public attention. When they are publicly noticed, children frequently experience different forms of stigma and discrimination, either in being liable to be excluded by their peers and local institutions (schools), in being looked down upon, or in being placed in institutional or other care separate from their remaining family and community.

The research was devised to begin to address these perceptions and behaviours by taking children seriously, seeking the views of children on their current situation and about their future lives and hopes. Children's issues were raised through a series of workshops with children, some research led and undertaken by children and a children's forum, all conducted over a seven- month period, from February to August 2004. Most of the children involved were themselves affected by HIV/AIDS and included orphans who had lost one or both parents. Children were articulate in raising and discussing issues and competent in carrying out interviews with others. They enjoyed themselves enormously, made friends and supported each other.

Children's definitions of vulnerability help to sum up the findings overall. The causes of vulnerability include not having supportive caring adults, such as parents and teachers, relatives, but these also are the experiences of children affected by HIV/AIDS especially those who have been orphaned. However, it is emphasised that having such family, relatives and other significant adults just existing or around is not enough: they need to treat children well and not beat them. Although material problems such as poverty, particularly resulting in not being able to pay school fees (and so not attending school), having no home, no food, and no clothes are both causes and conditions of vulnerability, emotional life and well-being is seen as being also, or even more, crucial to life. Thus, an important condition of vulnerability is being excluded, emotionally hurt and lacking self-confidence and self-esteem. This may be ultimately due to having no friends, no caring adults and no one to protect them, an isolation that is exacerbated, if not caused by some of the material conditions and treatment by adults. For children living in and from HIV/AIDS affected communities, the outcome of these problems is loneliness and uncertainty: overriding insecurity and uncertainty about the livelihood and lives in the future – will they have friends and family, will they be isolated and lonely, will they have resources to survive, will they understand the world?

Children's Definition of Vulnerability

1. Children having no father and mother.
2. Orphan (meaning loss of one parent).
3. Children being unable to pay tuition fee for school.
4. Children with difficulties in mind: children who had been emotionally hurt, and those with low self-esteem and self-confidence. It was said to include children being hurt in mind, a sense of being hurt, a sense of failure.
5. Children with no friends.
6. Children no food no clothes.
7. Children who are beaten by other people.
8. Children who are not good at study.
9. Children for whom no one cares or no one is concerned for them.
10. Children from a broken family (father and mother separated).
11. Children with no family, no home, no relatives.
12. Children without a good teacher.

MAIN FINDINGS

The main findings of the project relate to children's experiences and potential for exclusion, loneliness, isolation, uncertainties and their corresponding fears and worries for now and for the future. Children are most concerned about tensions and health within their family, friendships, stigma and discrimination, survival and the future of their families and themselves, and study – going to school and performing well. The feedback from children involved in the project show how the methods and activities used, including the approaches of taking children seriously, having fun, treating children with respect - participatory ways of working with children - were found to demonstrate and provide psycho-social support and personal development.

Worry

Children's worries permeate all of the issues and concerns they raise, and are linked to their actual or potential isolation because of stigma and discrimination, and general uncertainties about the future because of access to school and study, understanding what is happening in so many adults becoming sick and dying, and a lack of transparency about the disease because of stigma. These worries include:

Family

Children are worried about the health, welfare and survival of their family in:
  - whether a cure for AIDS and associated problems can be found,
  - whether family disputes, tension (and violence) will end,
  - whether their parents will die,
  - being able to care for parents and others,
  - who will care for them if parents die,
  - who they can talk to.

Stigma and discrimination

Children are experiencing and worrying about:
  - others looking down on them,
  - a lack of friends,

  - being ignored by adults and children in the community.

Survival

Children are worried about:
  - treatment and its costs,
  - having no food if parents die,
  - if they themselves are infected,
  - how long they themselves will live,
  - what will happen to them in the future.

Study and the Future

Children are worried about being able to study and do well at school in order to get a job. Children are worried about dropping out of school because of costs, stigma and discrimination, domestic work duties, or having to work to earn a wage.

Benefits for Children

The methods of work, in particular the participatory approaches used, were found to provide psycho-social support for children affected by HIV/AIDS and can be taken further and sustained over a longer period. The research work, workshops and the children's forum also demonstrated children's resilience. Some identified characteristics of resilient children include: strong attachment to caring adults and/ or peer groups, encouraging role models, socially competent at interacting with adults and children, plays actively, curious and explores the environment, and others. Many of these characteristics are aspects that were developed during this project work. The workshops and research provided a safe interactive social environment with newly met adults and children; the workshops involved play as well as discussion and some learning. It is the learning gained of the multiple benefits of these processes for children individually and socially that will inform work to be undertaken with orphans and children affected by HIV/ AIDS in the future.

The methods of work used included creating child-friendly environments (taking children seriously, listening to

children, reflecting their ideas and views), and encouraging children to communicate their experiences and feelings. These methods were found to:

· provide emotional support,
· develop children's self-esteem and confidence,
· support children's learning,
· enhance children's capacities in forming relationships and communication,
· act as a conduit for children's emotions in enabling their self-expression.

Future Work

Children don't want to leave their village. Children remaining in a familiar, identifiable community, with friends, attending school and maintaining family relationships is a primary aim, with the eradication of stigma and discrimination, and provision of social activities and support, and community networks as key objectives. This may be done by recognising children's actual and potential resilience through their participation in decision making in a safe environment. Because of the current experiences of exclusion of some children, and the need to provide support to children through processes of separation and loss, children's activity centres, properly facilitated with a central component of children's participation, can be developed, around which can be built a range of projects to address their concerns, from skill training to treatment, and are also points from which to address problems of prejudice, stigma and discrimination that are especially significant in children's lives.

Work will include:

· Development of children's activity centres
· Training staff and volunteers
· Developing a network of community support for families and children
· Anti-bullying work in schools
· Anti-stigma and discrimination programmes
· Support for orphans and their families to enable them to remain in their communities
· Access to education and healthcare.

My interview with Jie. When I went to his home he had just come back after collecting some garbage, he said his family had no money, his grandma was ill, his father had died and his mother had gone away. He has to collect garbage to earn a little money to buy a pen and stationery. When I interviewed him his grandma and younger sister both cried and he told me openly and honestly about his situation. I saw they only had about ten jin of wheat in their house, not enough for one week, and their house had collapsed. You can imagine for a ten year old boy to do all the cooking, looking after the four people in his family and collect garbage he finds around, he is in such a difficult situation. When I was ready to leave, his grandma cried. They had borrowed 20,000 yuan for his father's treatment, but in the end his father still passed away and his mother disappeared so he became an orphan.

1. INTRODUCTION

This is a report of the issues and concerns of children affected by HIV/AIDS in a comparatively small area in central China in 2004. The impact of HIV/AIDS in poor villages in this location is particularly severe. HIV was contracted by adults through selling-blood and subsequently spread through sexual transmission. The blood-buying entrepreneurs had bad collecting practices, mixing different peoples' blood before returning some to sellers. Many parents and other adults of reproductive age have died, many are dying and many are infected. Some children are also infected. Children are experiencing the severity of this impact emotionally and physically, yet have received only sporadic public attention. When they are publicly noticed, children frequently experience different forms of stigma and discrimination, either in being liable to be excluded by their peers and local institutions, in being looked down upon, or in being placed in institutional or other care separate from their remaining family and community. They may become and be treated as objects of charity and compelled, for example, to sing praises of donors, a form of institutional begging that ignores children's rights and development.

Children's Research

A children based research project was devised to begin to redress these perceptions and behaviours by taking children seriously, through seeking the views of children on their current situation and about their future lives and hopes. This research was conceived as part of the background to an integrated pilot project exploring child-focussed community-based care and support for families affected by HIV/AIDS. Children were articulate in raising and discussing issues and competent in carrying out interviews with others. They enjoyed themselves enormously, made friends and supported each other. Indeed, the reactions of children involved showed how the methods and activities of the project - the participatory ways of working with children, treating children with respect, and having fun - were found to demonstrate and provide psycho-social support and personal development, especially for these children affected by HIV/AIDS. The

main findings from this research are focused around children's experiences and potential for exclusion, loneliness, isolation, uncertainties and corresponding fears and worries for now and for the future. Children are most concerned about tensions and health within their family, friendships, stigma and discrimination, survival and the future of their families and themselves, and study – going to school and performing well.

The research was undertaken with, and by, children affected by HIV/AIDS (including orphans) in a largely rural area of central China in spring 2004. Children's issues were raised through a series of workshops, some research led and undertaken by children, and a children's forum, all conducted over a seven- month period from February to August 2004. Most of the children involved were themselves affected by HIV/AIDS and included single and double orphans (that is, children whose father or mother had died, or both parents had died). In addition, some other children from unaffected families and villages participated as researchers and their ideas, along with the views of other children from local welfare homes and local schools who attended the children's forum, supplement the main focus on HIV/AIDS affected children.

Responding to the HIV/AIDS Epidemic

This project on understanding children's perceptions was part of the initiation of work on children's issues in this area by Save the Children in partnership with government and other agencies. The programme is working on responses to children affected by a severe HIV/AIDS epidemic derived from practices of blood-collecting from poor people in a poor area. The epidemic has begun causing widespread deaths of young to middle-aged adults – including the parents and relatives of these children. In these circumstances, it is important to look to children's rights and ensure their care, protection, participation, and especially to prevent inappropriate institutionalisation of children.

The work draws from experience of HIV/AIDS epidemics

elsewhere in the world in addition to other, comparable processes of emergencies and situations where children become separated from parents. The multi-sectoral, multi-agency and child- focussed approach aims to:

- address stigma and discrimination;
- provide psycho-social support for children orphaned and affected by HIV/AIDS;
- ensure children's protection and participation, welfare and inclusion in local communities;
- ensure children's access to education and training;
- provide knowledge and skills for HIV/AIDS prevention among adults and young people;
- ensure children's access to healthcare, and provide knowledge and skills about care for adults and children.

(see West and Wedgwood 2004 for more background to this approach).

To undertake this work it is necessary to understand the local situation and particularly to understand children's circumstances and views. Parents and other adults nearly always assume, from their own perspective and past, what is best for children and make decisions based on these assumptions, rather than on an understanding of the reality of children's lives and views. Instead of making assumptions about children's lives, it is necessary to engage with them and work with them to fulfil their rights to protection and opportunities for development.

A Strange Illness

This report consists of seven chapters, and a summary. The background to the project follows, with a brief overview of HIV/AIDS in China, the effect of the epidemic on children, and the selection of the project site. The chapter on methodology of the research provides an outline of the general framework for child-led research and a short description of the process undertaken in this project.

The issues initially raised by children are described in Chapter Four, which also looks at their perceptions and definitions of vulnerability, and sets out their research priorities. Chapter Five gives a discussion of findings from children's research, compiled by an academic researcher involved in the project, taken largely from the results of children's interviews (their records), children's photographs and stories (a selection of which are published separately), and children's own analysis. Chapter Six gives an outline of the issues raised at the children's forum and a discussion of the benefits to children involved in the project processes and some of the implications of this for future work.

Chapter Seven concludes with a summary of main points and some consideration of what can be done in response to the issues raised by children and the benefits experienced in the process. Project work is already underway based on the results of this and other initiating work. This 'research' project is but part of an action programme and intertwined with ongoing interaction with children and other local residents: it is not a 'stand alone' piece of work. This report is a snapshot of a longer process.

The title, 'A Strange Illness', is how some children described HIV/AIDS, and summarises the problem. The illness is strange because many people do not know what it is, and do not want to name or discuss it: they are ashamed. It is strange because many people know that they or others are infected, but do not talk about it openly nor what will happen. It is strange because it cannot be cured or treated, consumes huge amounts of resources, yet people still die. It is strange because it causes stigma and discrimination, exclusion, isolation and loneliness. Also it is strange because the social effects are unpredictable and it leaves uncertainties, especially for children. During the research, children said that 'there is a strange, horrific, illness' and one orphan said 'my mother had a strange illness, because she sold her blood … she died some months later.'

2. BACKGROUND - HIV/AIDS, CHILDREN AND PROJECT LOCATION

HIV/AIDS and Children

The high rate at which AIDS is spreading globally has aroused some alarm around the world, especially in developing countries. In China, according to 2003 figures from the Ministry of Health, the number of HIV-infected people is 840,000 and the number of AIDS patients is 80,000, with a total of 1,000,000 (CCTV: 2003). Global experience has shown that children and adolescents are one of the groups of people most affected, because a great number of them have become infected with HIV, and because they are especially vulnerable to the impact of AIDS on families and communities. For example, the impact of AIDS on children is reflected not only by the number of who get infected, nor only by the large number of children who are being orphaned because either one or both parents have become sick and died from AIDS, but also on those who, before that happens, must act as carers or income earners for the family. Although most attention has focused on the difficulties of children who have been orphaned because of AIDS, other effects on children resulting from the epidemic have also attracted increasing levels of attention (Danziger 2000).

The specific aspects of the impact include the following. First, some children are infected with HIV. A report from UNAIDS (the Joint United Nations Programme on HIV/AIDS) points out that globally since the early 1980s, 90% of children who are AIDS patients were infected with HIV during pregnancy, through the birth process, or through breast feeding (China AIDS/ children 2004). Second, when parents are too ill to look after themselves and there are no other healthy adults available in the family, children end up looking after them, making sure they have taken their medicine, doing housework and even working for money. Besides these heavy physical and psychological burdens caused by increased responsibilities, children also suffer serious emotional distress caused by their parents' illness, weakness and deaths. Third, the AIDS epidemic may change many aspects of children's lives and their expectations of life. The stigma and discrimination related to the epidemic in specific countries and communities may cause many additional difficulties for children.

Orphans

According to estimates, the current number of children orphaned worldwide because of AIDS is 16,000,000, and this number will increase to 30,000,000 by 2010 (Phoenix Weekly 2003). Experts from the Ministry of Health in China have forecast that the number of children orphaned because of AIDS in China will reach 260,000 by 2010. But already there is a huge growth in orphan numbers in areas where the epidemic is severe and concentrated in some parts of China (Voices 2003). According to the figures from research involving 143 HIV infected people in some areas of China, 16.8% of infected people have children younger than five years old, and these children will become orphans when they are still minors (Joint Assessment Report 2003).

The forecast huge increase in children orphaned by HIV/AIDS could present a strain on existing welfare services for orphans in China. The total number of orphans in China is not known, because most are cared for informally by relatives, but the number living in this 'kinship care' is likely to be over 400,000 (pers. comm., from current research estimates). In 2002, the number of orphans and abandoned children in care of the state was about 54,550 (MoCA 2003). They are currently cared for in residential care (in large welfare homes or in small group 'family' homes spread throughout a town), or foster care. Many are also adopted. Government policy is to increase foster care and reduce residential care to a minimum, with existing large welfare homes becoming support centres for community- based provision. However, the projected growth in orphan numbers poses a challenge to the policy shift, if there are no mechanisms available for expanded community based care, nor sufficient carers. By 2003-04, a count from the statistical yearbook (MoCA 2004) reckoned that the number of orphans and abandoned children in the care of the state had increased to 59,733. Proportionally, this is a huge increase, which may be due to greater awareness of, or increases in the number of, children orphaned by HIV/AIDS, although various other factors might be involved.

The growth in numbers and the visibility of children

orphaned through AIDS has been found to attract beneficial public attention, but also inappropriate responses that are detrimental to children's well-being now and for their future (see West and Wedgwood 2004). In 2004 a coalition of international agencies and governments produced 'The Framework' for guiding responses because of these problems (see Framework 2004). In China Save the Children has been working on HIV/AIDS issues and with children (and also on what are related issues of child protection) for almost a decade, particularly focussed on prevention through peer education and the development of holistic, multi-sectoral models of prevention, care and welfare (see SC CPN 2004).

The circumstances experienced by children in parts of central China where the HIV/AIDS epidemic is severe and concentrated have raised new problems for children. From the initial visits to the area, and from knowledge of the effects of the epidemic elsewhere, such problems are known to not only concern children who have been orphaned, but children having sick parents, and having to care for their family. Other problems relate to children's poverty, problems of survival, the possibility of them becoming separated from their community and them ending up on the street, or their placement in inappropriate residential care. On top of this, they experience grief and emotional stresses in dealing with these material problems, family deaths and loss.

Although these problems might be known from elsewhere, or roughly gauged from initial visits, the reality of children's lives, the problems they actually face, can only be ascertained through talking with the children themselves. However, in most countries (and in China) children do not usually experience such attention from adults, in being taken seriously, listened to, and having their ideas and opinions respected. In addition, children from communities and families affected by HIV/AIDS are likely to bear additional burdens and not find communication easy. The process of working with children on research, finding out their views and circumstances, is also a process of engagement that needs some long-term commitment, especially with children in distressed and difficult situations.

Project Location

The selection of the site for any pilot intervention should be a location where continued support to children can be offered and provided. Save the Children has been working in Anhui Province for over a decade with an office base in Hefei and a qualified, experienced and competent staff team, familiar with protection issues and community-based work.

Anhui Province is a big agricultural province of China. Since the first AIDS case was discovered in late 1994, the total number of reported HIV-infected people, in 15 cities and 52 counties (or districts) of Anhui Province, is 1558, with 344 AIDS patients and 186 deaths to the end of September 2003. According to the estimates of some associated agencies, the characteristics of the AIDS epidemic in Anhui province are:

1. Most HIV-infected people were infected through illegal and substandard blood collection activities in the early 1990s.
2. Most people who are infected are based in Northern Anhui.
3. Most people infected are agricultural workers in poor areas who are short of money.

Becoming infected with HIV through blood selling is a situation unique to China, and the situation of AIDS in central China was not known until recent years. This is partly because the attitude of the Chinese government has opened up in recent years, but also due to the seriousness in these areas of the continued spread of AIDS (Anhui Daily 2003).

In China, Anhui is not the province most seriously affected by the AIDS epidemic, although more and more people have tested HIV-positive in recent years. But in some parts of the province the problem of AIDS is very serious, especially in north-west Anhui. It is important to undertake research and intervention activities. Most infected people in this area (and in the neighbouring province of Henan) were infected through blood-selling transmission, which has had a different timing and spread of impact to the usual modes of transmission through drug use or sexual

activity. The centre of the general epidemic derived from blood-selling is better known as being in Henan, but its radius encompasses north-west Anhui with a focal point in Fuyang prefecture, bordering Henan. To research and develop efficient intervention strategies for this part of Anhui should have significant and innovative benefits, especially for replication in similarly affected districts, and provide lessons for provision elsewhere.

Fuyang

According to the forecast of experts in China, the AIDS epidemic in China has entered fourth period - the period characterised by outbreaks of opportunistic infections and death. In some seriously affected counties and villages of Henan and Anhui Provinces, these opportunistic infections have begun to break out and massive numbers of patients have died since 2001 (Joint Assessment Report 2003). Problems related to AIDS in Fuyang City, Anhui, are increasingly attracting public attention. Save the Children has developed a good cooperative relationship with many government departments in Fuyang, such as the Working Committee of Children and Women (WCCW) and the Anti-Epidemic Station (AES), which provided good conditions and opportunities to start research and programme work in this location.

In Anhui Province, the majority of HIV-infected people are concentrated in Fuyang City. Through the estimates of recent years (interviews, Fuyang Anti-Epidemic Station), it appears that 10% of people who sold blood became infected with HIV. In the early 1990s blood selling was at its peak. The rate of local farmers who sold their blood was very high. At that time, there were blood-collecting stations in Fuyang. Some farmers also went to Henan or Tianjin to sell their blood. In recent years, however, the rate of sexual transmission has increased. Village leaders have reported that usually it was the women who first went to sell their blood. Once she had begun blood-selling, she would tell relatives that this is a good way to make money, and generally a whole family would become involved and so be infected. A local idiom had it that '*once a person stretches their arm* [to sell blood] *they will get*

50 kuai [renminbi] *and after buying food still have 40 left'*. In poor rural areas blood-selling was an important means of earning cash, since agricultural work produced food to eat, but not cash. So the best way of earning money at that time, for example to pay for children's education, was selling blood.

At present, four counties in Fuyang have become national ChinaCare (a government project under the Ministry of Health) 'Pilot Model Areas on AIDS Prevention and Treatment'. AIDS patients have been able to obtain free treatment since June 2004. More than 120 people have begun taking medicine since this time. As early as 1996, the government published measures that included efforts to make a long-term plan, to establish a leading committee in Fuyang government, and to provide 100,000 yuan as the special contribution from the finance authority. From March 2004, the Fuyang Government published local policies in accordance with the national policy 'Four Free and One Care', which includes the promise of free treatment for AIDS patients, life subsidy, free education for children orphaned because of AIDS and so on.

However, it has been found that some HIV-infected people as well as some of the general population still have a very low awareness of AIDS. They lack knowledge of AIDS and skills for prevention. They also have limited awareness of the danger of AIDS, and little understanding of the impact it can have on society. What concerns AIDS patients and HIV infected people most is not their health, but life and money, and especially the impact that AIDS can have on families and children (Ji 2003). At present, in general, the work and programmes on HIV/AIDS in Fuyang are struggling with many problems and challenges. The problems of discrimination, and the lack of understanding about AIDS are very serious. Children affected by AIDS are not being understood and nor are they being protected. Little of the work on prevention and treatment currently being carried out in Fuyang is focused on children. It is essential that any intervention activity for children should be based on evidence from research that includes these children's perspectives.

3. METHOD

This research was child-focussed and child-led. Decisions on the research issues were led by children although the activities were at least initially facilitated by adults (the research and support project was initiated by adults). The main aim of this activity was to enable children to express their ideas freely, to pay great attention to children's views and to encourage children's enthusiasm for pursuing their ideas and making decisions. Children's participation here means that the design and content of the research project were undertaken through children's involvement and decision-making. In this project, children identified issues, prioritised them, developed questions for research, designed interview schedules, selected interviewees (other children who they identified as vulnerable, or facing difficulties), and then collected their materials together, reflected on their experience, analysed their findings and drew conclusions.

The background to this research is not only children's rights but the realisation that children themselves are social actors. That is, that children engage with others (children and adults), influence the environment and others around them, and that their perceptions of the world, their views, ideas and opinions need to be taken into account in order for any project or intervention, policy or practice, to be successful. Thus, children's participation is not merely a question of meeting children's rights but that there is a practical reason for children's participation and this particularly includes research. Many international intervention programmes on children and AIDS are increasingly emphasising the importance of child participation, and so successful experiences in this area are slowly emerging.

This particular project aimed to understand children's lives and circumstances, issues and ideas through children defining research questions and through the process of facilitating that research. The adult facilitators were also able to make observations and record additional material through the whole process of the project, including facilitation of activities, private discussions with children, and so on. A major emphasis was on creating child-friendly environments (in terms of behaviour, attitudes

and so on) to enable the work to proceed, and producing quality material (see West 2003a , 2003b and 2005b and Zeng, Yang, West 2004) for further discussion of children's participation linked to China. The term 'children' as used here refers to human beings under the age of 18 years, an internationally accepted benchmark defined in the United Nations Convention on the Rights of the Child (ratified by China in 1991). This criteria is often at some variance with local ideas, for example here, given that many migrate out for work by the time they are 16 years old. In addition, many older children do not like to see themselves as 'children' but rather as 'young people'. However, since most of the children in this project were aged under 16 years, the term 'children' has been used in preference to the more cumbersome 'children and young people'.

General Stages in Children's Research

The general method for this research consists of the following stages.

- First, selection of participants (which may include self-selection), meeting together and agreeing purpose of the project and ways of working.
- Second, children raising, sharing, discussing and identifying issues and problems of particular importance and concern in their lives.
- Third, children agreeing, refining and prioritising a common set of issues.
- Fourth, children transforming themselves into researchers and the issues into research questions and devising methods and tools (such as interview schedules).
- Fifth, children conducting research.
- Sixth, children collating the materials, reflecting on the process and doing some analysis.

Subsequent stages might involve children in production of any communication materials (such as reports or videos) or making presentations of their findings. These stages would be decided by the children themselves or at the outset of the project, depending on the purpose of the work.

This structure might vary according to children's decisions, the aim of the project, and so on. The degree of involvement of adult facilitators varies also according to a particular project, but often includes the adult facilitators supporting children throughout, particularly where participatory processes are little known and such projects innovative, as in China (see West 2005b for further discussions of method and approaches).

As in this project, the research might include a number of different methods, although it has been found that children often like interviewing other children. In this project, children also took photographs of villages and recorded their reasons for taking particular pictures. Discussion of the pictures formed part of the research materials. This research was later followed by a children's forum, and some of the outcomes from this activity are included here in this report.

Outline of Research Process and Forum

This research project involved working with a group of children who were particularly quiet and introverted at first, and especially so even given the Chinese context, where children's usual experiences of interactions with non-family adults are at school, listening and following directions given. In order to facilitate the research and create an environment for children's participation the adults needed some preparation.

The selection of children was undertaken by local staff and contacts of the Fuyang Women's Federation, and was aimed to have a balance of boys and girls from each location. The Women's Federation requested selection of twenty-eight (28) children aged between 13 and 16 years from Yingzhou District, Funan County, Linquan County, Yingshang County, and the Special Economic Development Zone of Fuyang. In fact the age range of children attending was from 9 to 18 years, but the majority were aged 12 to 15 years, with three aged 16, 17 and 18 and three aged 9, 10 and 11 years. The oldest boy, aged 18, took part only in the first stage activities. Most of these children were affected by AIDS to differing degrees,

including having sick parents, having other relatives infected and being orphans. Since most of the children were attending school, and following principles of working with children at their preferred time, the project groupwork was done at weekends.

Basically, this research was made up of three weekend activities, and one month of children's research. The first few stages were conducted over two consecutive weekends in March 2004, followed by a period of some five weeks spent on research, and then a follow up weekend in April on analysis. The children's forum was held in August 2004, during the children's holiday from school, and preceded by a few days preparatory work.

Preparation

In order to ensure children were comfortable with implementing the research work the adult team themselves spent almost one week on preparation including some training at the beginning of the activity. This preparation work involved developing an understanding of the meaning of participation, how to relate to children, the situation of the AIDS epidemic in Fuyang, an idea of the circumstances of these children, and other points concerning both local contexts and childhoods, and ways of working with children. This provided the foundation for designing the first stages, which focused on becoming familiar with the children and gaining a basic understanding of their situation.

First weekend – first stage, developing children's participation and identifying children's issues

The first weekend activity (12th –14th March) was initially about encouraging children's participation, enabling them to get to know each other and the adults, and work together. Through drawing, introductions of themselves and the situation of their villages, they gradually became familiar with each other and grew used to expressing their ideas, minimised the gaps and barriers between each other and actively took part in the activities. The adult team gained a great deal of information and insight into children's lives, and in particular their main issues and concerns.

Second weekend – second to fourth stages, including children's definition of vulnerability, children's research issue priorities

The second weekend's activities (20th –21st March) consisted of deciding priorities for issues and preparing for research. Children worked on themes such as how to recognise what is most important and what concerns children the most, what questions they should ask and how to ask others these questions, how to find suitable interviewees, and what they should pay attention to during an interview. The children also discussed what vulnerability might mean, partly to provide their perspectives but also as a preliminary to their own selection of interviewees, who would be children who were vulnerable and living in difficult circumstances. Children also practiced skills of interviewing, and they felt excited about facilitating their own interviews. Over this weekend, the children designed interview schedules covering four aspects: studying, health, future, and family. Rather than researchers, they were known as 'Little Journalists'. Every child was given a camera to use.

During the second weekend, the children had a chance to become more familiar with each other. Some of them became close friends and talked about everything together. They also developed a lot of trust and rapport with the adult facilitators, and 'they were willing to tell us the words and feelings from the bottom of their hearts'.

Research

The following month was allocated as the time for children to undertake their research. One adult visited all of the children twice in their villages to provide support and monitor progress. In addition, she was able to gather further information about children's lives, circumstances and local conditions to contribute to the overall research and planned intervention project Any problems that arose for the children were raised during the visits, and resolved through discussion with the children.

Third weekend – research compilation and analysis

The third weekend activity was from 23rd to 25th April. The weekend was spent in discussing research findings, checking information in children's interviews (171 had been completed in their villages) and recording information from the photographs. Children spent time discussing in groups and deciding on the framework for this report.

A Note on the Children's Forum

This forum was held in August 2004 and consisted of children from the research group, joined by six children living in residential care, presenting their issues to a group of Fuyang Government officials. Sixteen of the 'Little Journalists' research group attended, those whose families are and were directly affected by HIV/AIDS and who had been very active in conducting research. Six children from middle school came and made presentations on HIV/AIDS peer education at the start of the forum preparation sessions. Two children from the middle school stayed on, and later made speeches to government officials on the living circumstances of the researchers, which they had discovered for the first time through this meeting. The children from residential care had been living in a large welfare home, but were now in six small group units, forms of family type care in flats in the community, spread across the city. (These small group family homes are a development organised and sponsored by Save the Children as part of a process of breaking up and changing large-scale institutional care, in this case, by taking the opportunity to respond to the flooding of the residential welfare home).

The preparation period was spent in children getting to know each other and their backgrounds, and included drawings, artwork, games. The 'Little Journalists' and the children from the small group homes decided to communicate their ideas and issues through drama. They devised topics, and worked in small groups on scripts and scenes. They finally produced six dramas, four by the 'Little Journalists' and two by the children from the

small group homes. They also managed the staging of the whole event, including introductions.

Only some findings from the forum are included in this report, and not a description of the whole event, nor of the children's dramas.

Research Outputs

The research process with children produced the following outputs:
- · Children's issues
- · Children's perceptions of vulnerability in childhood
- · 198 interview records in total (including interviews the core group did of each other)
- · Additional essays by children
- · Photographs and associated commentary

In addition, the adult facilitators could provide:
- · notes through the research process from discussions and observations with children etc.
- · notes from visits to villages

All these also contributed to the preparations for the proposed future programme of work. Further materials were subsequently gathered from children, in particular information from the forum including children's artwork, notes from their dramas and film of their presentations. Most of the research groupwork processes were photographed and video-filmed.

When I interviewed my classmate Wei, he cried because his elder brother needs a lot of money to pay for the high school tuition, his mother has got heart disease, his younger brother and himself also need money for their tuition. His father is the only bread earner in the family. Although his father could find a job, his income was not enough for their tuition. His mother has been getting sicker because they cannot afford the medical fees. When I interviewed him, his younger brother went out to collect garbage for buying some study articles and they never bother their parents about this. When they have difficulties, they will do their best to solve them. His mother told me with tears in her eyes, 'you should tell others to help people in difficulties like us.' I was touched and cried after listening to him, so this impressed me most.

Jie's parents have both died and now there is only his elder sister, his eighty year old grandma and him who are in the unhappy family. He only used to have to pay half his tuition fees but now he gets them free charge. Because of poverty his elder sister cannot afford to go to school, and has to work to support the family. His grandma goes to church everyday to beg God to bless them with a happy life. They only have a small house made of mud in which it is quite cold. He seemed to cry when I interviewed him. My tears also burst out and I felt very sad on my way home.

4. CHILDREN'S ISSUES, RESEARCH PRIORITIES AND PERCEPTIONS OF VULNERABILITY

This chapter is concerned with the issues raised by the core group of children, which are arranged in sequence following the development of the workshop. The three stages in raising issues were:

· the initial issues raised by children;
· children's discussion and definition of vulnerability;
· children's priorities of issues and refinement of these into research questions.

The next chapter looks at the result of children's own research and draws on the initial analysis and findings by children from a further meeting, in addition to the interview schedules they completed.

The core group of children were the 28 from the five locations in the Prefecture, 12 boys and 16 girls, and most aged 12 to 15 years (see above). The majority were children orphaned and otherwise affected by HIV/AIDS.

─────────────────

Yang lives in the same village with me. She leads a hard life. Her grandma has passed away. Her mother is now lying in bed and cannot move because of illness. I asked Yang if she does the cooking everyday, she said she does and also washes the clothes by herself. She is now a middle school student and gets high grades at school. After school she will prepare the meal for herself and her mother. Her father is a migrant worker in another city. Currently she lives with only her mother.

─────────────────

CHILDREN'S ISSUES

The initial issues raised by children through drawings and discussions indicate a breadth of concerns from the big (such as world peace and the environment) to the particular (such as family life, and school). Throughout the discussions over the first two weekends, and subsequently through the research, the major issues remained consistent, and the list produced at first shows some of the interconnections between different areas of children's concerns, and indicates how they link up into a perception of the world that is different to that of adults.

The main issues and concerns raised by children were shared between them, and then grouped by them and given headings. These groups or categories suggest something of children's classifications of their local world and environments. For example, one major heading, of schooling, is focussed on issues to do with performance at school, relationships with teachers and education. Problems concerning access to school because of tuition fees, and the general hygiene of the school environment, were placed separately. This division indicates a series of alternative categories, for example because children did not put all matters concerning 'school' in one heading but separated out access to school, and the physical environment of the school, from the work of school. Thus, the classification chosen by children emphasises the importance of study and test scores at school, a topic to which they returned in subsequent discussions. The processes of the workshop in identifying issues are not discussed here, but some indication is given in chapter six, looking at the benefits for children of these workshops.

The groups of initial issues identified by children are given below, but they are not listed in any order of priority. Children later reviewed their issues and these groups/categories and decided on priorities, which then formed part of their research questions and the development of interview schedules.

Schooling

This included issues around scores and performance at schools and criticism by teachers. The question of school marks was a cause of worry: '*worry that my school performance and marks will get worse*'. Concern over school performance in general included worry that they would not understand the lesson, worry that they don't know how to draw. These were linked to worries about the teacher, fear that they would be criticised by the teacher, and '*worry that the teacher will ask me to answer the question*'. These fears and worries about performance at school and criticism clearly played a large part in the lives of those children attending school but also indicated the importance of school and the probable difficulties for those who were excluded, who cannot attend. Despite the fear of criticism by teachers, one child at least saw them as important figures, and worried that '*the teacher would move to another job*'. It is clear that the role of teachers is potentially very important in the lives of children, but much depends on the character and values of the teacher, their teaching style and methods, and the nature of their relationships with children. From children's perceptions teachers seem to fall into two broad groups. First, those teachers who criticise a lot and ask children to study harder. Second, those who are closer to children and do play a more important part in their lives, in making themselves open and available so that children will share their thoughts and concerns with them.

Friendship (lack of)

This was largely concerned with a lack of friends and being ignored by classmates. That children had become '*separated from friends*', that '*no classmates or schoolmates will play with me*' and that they '*cannot have many friends*'. The classification of this issue was the subject of some debate, with some children saying it should be called 'social life' but others insisting that it is 'friendship' (youyi). The issues and discussion raised here clearly prefigure other issues, that could be expressed differently as 'stigma and discrimination', but the importance of the perspective from children is simpler and personal – a lack of friends, which appears to be relatively recent and not an experience of long duration, because of the change in circumstances that is implied.

Family

This grouping or category might be said to concern the broader well-being of the family through relationships and income. (Other issues concerning the family were grouped elsewhere, in particular under the category of 'physical health'.) Children raised problems of disputes between their parents and disputes between other family members as important issues to them. They were also concerned about their own role, and some fear of upsetting any equilibrium was implied. '*Do something wrong and the granny will be angry.*' Children highlighted the problem of them being misunderstood by family members. Although this category was principally concerned with the nature of relationships and behaviours toward each other of members of the family, children also included in it the problem of 'no living expenses', apparently seen not only as a source of tension, but also as another threat to the survival and well-being of the family.

Physical Health

Although the category of 'physical health' was not placed next to that of 'family' (on the wall in the workshop), there are some links. The health of members of their family, in particular their parents, siblings and grandparents was of great concern. Individual children noted, for example that their elder sister was ill, their father is ill, that they were concerned about their mother's health, that the illness of granny was a worry. Thus, children raised the issue of health not as a general or abstract problem but through specific experiences. This broadened out to a concern by some for the 'health of the teacher', again showing the interlinking between categories since this is a parallel to the loss of a teacher noted under 'study' above (the teacher moving to another job). But children also raised a fear for themselves under this category, that they themselves would not be in good health, a simple statement that perhaps suggests a great deal about children's experiences of life, characterised by the ill-health and sickness of others, and consequent unhappiness (perhaps also linked to problems of lack of living expenses). It is interesting to note that a great many of the drawings by children concerning life now and in the future included pictures of hospitals and doctors, and several noted their ambition

to become a doctor.

The issue of physical health was also linked to problems of diagnosis of the illness and the amount of money spent on medicine and treatment. In the experience of some children, when there was a person in the family infected by HIV/AIDS, and they went to the hospital, HIV was not diagnosed. The family then spent lots of money on various attempts at treating the illness, and built up debts. Many adults apparently believe that the lack of diagnosis was done on purpose in order for the hospital to make money from other treatments. Children's concern with physical health is thus clearly bound up with other issues. They worry that their carer will leave them and that they cannot stay on in the village, and no one will look after them. The issue of being 'looked after' includes access to school and food, because parents made the money to pay school fees and to get food. These worries are closely linked to another category - children's lives in the future.

Future Lives

In general, children's ideas of their life in the future were full of uncertainties and failures, their concerns over what they could not become. Much that was raised under this grouping was about jobs, and some children at first said that it should be called 'occupations', but others argued that because other issues had been included 'future lives' was a better and more appropriate title. Some children had specific ambitions they wished to fulfil, such as being a singer, teacher or businessman, that they feared they could not become. Some concerns were more general and children worried simply that they could not find a job when they grow up. Others were concerned that they could not go to university, but some looked in the more immediate future, with linked worries – that they cannot go to school. Apart from uncertainty over what they would do, some worried about where they would stay in the future (what sort of shelter). Concern for the future was not limited to themselves, for example, as one child noted, there was a problem of 'elder brother's work'. Again, these problems are interlinked with having enough income in the family in general (hence the concern over

the work and contribution of the elder brother), and so implicitly concern the health of all family members and their contribution to family upkeep. But the issue of future lives also includes worries over study, and probably issues of self-esteem or self-confidence given the general worry about unfulfilled ambitions. Children's focus on school was because many saw this as the only way to learn skills to support themselves in the future. They worried that if they stop studying they would not have the skills to live an independent life and feed themselves.

Other People's Bad Behaviour

This was highlighted as a specific category and primarily concerns violence in the family, and violence at school from older children, bullying. Although violence almost seems to be accepted as a fact of life, the experience and issue was also deemed of sufficient worth to be raised and emphasised as a separate category, and although not one subsequently pursued separately in the research, it remained an underlying concern. The 'bad behaviour' of the title of this category is being beaten by 'other people', and being beaten by father and mother.

Ungrouped

In addition to the issues grouped in categories above, there were also a few which the children did not feel fitted under any heading. Although two might be thought to concern school, they were placed separately. The hygiene of the classroom, and of the school environment in general was raised as a problem. Another major problem is having no money to pay tuition fees at school (or problems in meeting the costs of fees to attend school). Children said that this was a different category of problem to those listed under 'study' (some children did not attend school because of fees). For some children there was a general perception that their village cannot be well-off, a reflection perhaps not only of the economic status, but also the current circumstances of health and death in the village. Children also raised issues around the environment of the village, and this was not only about the physical environment, but also the spiritual or emotional. One child said that frequently in her grandmother's village, people died, and this was quite a stressful environment.

These environmental concerns were linked to issues of natural disasters, although they were not placed in the same category. Children also noted that more people were turning to religion. One other major problem could not be grouped elsewhere - world peace.

Natural Phenomenon and Environment

Finally, children noted a set of problems they placed under the category of natural phenomena (although not natural 'disaster' since some events, such a floods, are a comparatively regular feature of life in some rural parts). Apart from flood, fire and running out of resources were listed.

These issues and categories were prioritised and further refined in the second week to be used as the basis for research work by children, see below, 'Children's Research Priority Issues'.

═══════════════

The thing impressed me most is once during my interview an old woman cried and told me their difficulty, she said they had no money to see the doctor and pay the tuition for the children. Her son has passed away, and her daughter in law has mental disease, they do not have enough food to eat, she begged me to help them to solve the difficulty, I was deeply touched.

═══════════════

CHILDREN'S PERCEPTIONS OF VULNERABILITY

In the second week the child participants also looked at what is meant by vulnerability (difficult circumstances) for children. The project had begun with the understanding that children would interview other children in difficult circumstances, sometimes expressed as 'children who were vulnerable'. Although there was a general understanding of the target group for research, and children were enthusiastic about conducting interviews, some time was spent by children defining what made children vulnerable or in difficult circumstances. This material is included here as another aspect of children's perceptions and understandings of their communities.

The definitions of children they included as vulnerable were set out under twelve headings with associated reasons why. The first two have been placed together, because the reasons were the same, and both concern the death of a parent. The term orphan was used as meaning the loss of one parent, which was seen as making children vulnerable, and so they also listed children having no father and mother separately.

1. having no father and mother; and

2. orphan *(meaning loss of one or two parents)*

Reason for both 1 and 2: that children have no one to care for them, no economic resources, and no one to 'back them up', meaning no one to support them, or love them.

3. being unable to pay tuition fee for school

Because this means that children cannot go to school, they cannot learn knowledge, and so the future will be a problem because they cannot find a job.

4. children with difficulties in mind

This phrase was essentially defined as children who had been emotionally hurt, and those with low self-esteem and self-confidence. It was said to include children being

hurt in mind, a sense of being hurt, a sense of failure: children who have been frustrated.

The reason given for this making children vulnerable was that they cannot bear to experience failure or difficulty again. Also, it was said that they need other people's encouragement (which suggested that without such encouragement they would remain vulnerable).

5. with no friends
Children with nobody to play with her or him, lonely and isolated, nobody to talk to, nobody to help, children who cannot have a heart to heart talk with another.

6. no food no clothes
That is, children who cannot eat enough, cannot have enough clothes to wear (the winters are cold).
The reason is that these children will be ill and their health will be in danger.

7. are beaten by other people
These children have nobody to protect them.

8. not good at study
Being not good at study was defined as having scores that are not good, rather than other measurements of knowledge, skills and understanding. This is because the teacher will criticise them and other people and children will laugh at them. It is not good for their future. Parents will be angry at them, and it will upset parents.

9. no one cares or is concerned for them
The children are lonely and isolated, cannot feel the warmth from others, nobody is concerned for them, nobody is there to help them.

10. broken family (father and mother separated)
Because of this separation the children (and parent(s)) will not be in a good mood and therefore it will have negative impact on their study.

11. no family, no home, no relatives
Because there is no one to care for them, there are no economic resources, there is no one to back them up (support them, love them).

12. no good teacher
(that is the children don't have, or the school does not have, a good teacher.)
Because this is the same as having nobody to teach them, and they will not be good at study, and in the future will not be knowledgeable.

These twelve headings look both at causes and at conditions of vulnerability. Causes include not having supportive caring adults, such as parents and teachers, relatives, who, it is emphasised, treat them well and do not beat them. Material problems such as poverty, not being able to pay school fees, having no home, no food, no clothes are both causes and conditions. But an important condition of vulnerability is being excluded, emotionally hurt and lacking self-confidence and self-esteem. This is ultimately due to having no friends, no caring adults and no one to protect them, an isolation exacerbated, if not caused by some of the material conditions and treatment by adults.

═══════════

The most unforgettable thing in my interview is, his grandparents kept crying, and I cannot go on my interview. They said their family is too poor, the child is pitiful, when the children were very young their parents passed away, and the children did not have a good life with the grandparents. When I left, the grandparents said: " we hope you could help our children, I have no money to pay the tuition for the children, we don't want them to drop out, they are top students in the class." I hope I could help them to go to school.

═══════════

CHILDREN'S PRIORITY RESEARCH ISSUES

The children were asked to decide priority areas, with a suggested target of five. However in the process it was clear that there were four main priority areas, scoring very close to each other (17, 18, 16, 15 votes) and the fifth was far behind. So the following four priority issues were used as the basis for the interview schedule subsequently developed by the children. The questions on the schedule reveal something of the discussions and the nature of issues for children.

Study

This seems to be a very important area for most Chinese children, but the issue here is tinged with problems of poverty, discrimination and the future. The discussions focussed on what happens if children cannot go to school? What can be done about it? And if they do go to school, what if they cannot afford books or other materials to study? If they do attend school but do not do well, then how will they be treated by the teacher and their classmates?

It is clear that sometimes parents (father or mother) do not let children go to school. This indicates not only reasons of poverty but that some children are withheld for housework or other domestic duties, or that some children are withheld on grounds of gender rather than, for example, a prioritisation of attendance by birth sequence. The question of what will be done in these circumstances partly concerns children seeking their own solutions, for example in working to earn money to attend school or for school materials. These issues of domestic or other work shed a different light on the question of what will teachers or classmates do if children do not do well at school?: children may be tired from other work and not have so much time to devote entirely to their schoolwork (an important consideration, where so many children in China have large amounts of homework and additional classes in the evenings and weekends, because of pressures on getting good scores). One child reported that in primary school there were generally more girls

than boys, but in middle school more boys than girls. One boy mentioned that his two sisters had to stop education to go to Guangdong province to work to support the family.

Given these difficulties faced by some children in attending school, the issue of the importance or benefit of study was also raised, for example, in terms of the future life.

Health

The health issues did not explicitly name HIV/AIDS or 'the strange illness' but were principally concerned with what happens when people become ill. These health issues remained focussed around the family and can clearly be seen as indicative of bigger concerns over care for children, care for the family and different responsibilities, and particularly the topic of the impact of health on life and study (the latter again reinforcing the importance of study). When people become ill, including children, then who looks after them? What do people do and who supports them if someone gets a 'hard-to- treat disease'? The children also recognised the different importance of different family members being ill, and in the research questions aimed to identify which (if any) family members were ill, and what kind of illness.

Future Life

The discussions in this area can be divided into two strands, which were also reflected in the questions devised by the children. The first strand focussed on children's ideas, their desires or hopes for the future, in terms of job, environment and family. The second strand was concerned about their capacity for this and how realistic these hopes might be.

The first strand of discussion links to a broad range of issues in children's lives, some also raised as priorities. The question of what sort of job children would like to do is linked to how well they will do at study. Some children had earlier expressed interest in becoming doctors and this requires some study, which translates in practice into scores at school, which in turn need attendance at school, access to books and materials and time. Ideas around future family reflect the concerns about existing families,

and particularly children's worry that they will also succumb to disease before the age of 40 years. This is because, as one boy noted, his worry is how long he will live, because most adults in his village are dying before they reach the age of 40 years. This boy wonders about his life, but in the context that because of HIV/AIDS some children's understanding of life expectancy is less than 40 years. Thus, children's ideas about their future family not only involves their own partnerships and possible children, but implicitly there is a concern for older family members who are now ill or dying (and for some, who have already passed away). The question of 'hopes for the future family' are as much about threats being faced now as hopes and ambitions. Similarly, the question of environment concerns broader issues than a concern for environmental issues as raised by many children not only in China but around the world. The environment in rural areas includes unworked fields and decaying surroundings because of the extent of illness and death, and also includes the composition and life of the community in which children live and which is being completely restructured because of HIV/AIDS.

The second strand links up the future and the present, and perhaps might be seen as raising children's fears rather than their hopes or desires. Discussion focussed on whether children felt they could live an independent life when they grow up, which again implies all sorts of constraints in the present that impact on the future. These constraints include learning from school, and suggest also the recognition of diminished inheritance not only in terms of money and goods, but in terms of learning other skills and behaviours that concern trade, dealings and relationships. There is something implied of a sense of diminished importance of children affected by HIV/AIDS because of what is happening to their family, which might be linked to the other main area in this strand, of being confident about the future. Here it seems there was some distinction between those few children not personally affected by HIV/AIDS, who were more confident about their future, with more sense of personal confidence and security, and goals for occupations that were achievable. This discrepancy serves to highlight the issues for the

future raised by children for themselves, their peers and others in villages affected by HIV/AIDS.

Family

Issues around the family were greater in number and revealed a whole range of concerns. Direct problems to do with family members' health were not touched upon, being covered in the 'health' topic. Instead, issues included other problems such as children's role, work and relationships within the family domestic tensions, and problems.

Children's role was bound up again with study and the question of the attitude of other family members to children's study, that is them going to school and having time and resources for study. In addition, children's place within the family was raised, in whether anyone paid any attention to their ideas. This might be linked to children's lack of role within the community, where they reported that some public meetings were called, but they were not encouraged to attend to hear about events and issues. Children expected other children to be allocated housework or domestic duties, and this formed one of the particular questions for the research.

Children's relationships within the family were linked to attention paid to them, and also to their feelings about family life and in particular whether they were lonely. Relationships within the family were of concern, particularly between parents, and the subject of them arguing or quarrelling even over something small. That families face difficulties was acknowledged, also that these varied and have differential impact. In terms of difficulties, children were interested in the potential roles that children could have in seeking solutions.

5. CHILDREN'S RESEARCH FINDINGS

This chapter looks at the results of children's research, is drawn from feedback and analysis by the children, and some later analysis of their work by an adult facilitator (who is also an academic researcher). The aim here was to learn the situation of children who are affected by HIV/AIDS. Not all of the 28 children who acted as researchers are from families affected by HIV/AIDS. In this chapter, the situation of children affected by HIV/AIDS is the main foundation and that of children from other families facing difficulties has been used as comparison. Thus, the situation of children from Funan, Qiandingying, Liulicun and the Special Economic Development Zone is the basis for analysis and that of those from Yingshang and Linquan is for comparison.

In the third weekend's activity for sharing conclusions, an important aspect was children's discussions in different groups on what topics children are most concerned about, the common difficulties in their villages and how to overcome these. The outcomes of those discussions are outlined in order below according to the conclusions from the children, so beginning with the questions and issues of most concern to the children. The findings fall under five headings, as follows.

(1) Whether AIDS can be cured

For most children, whether AIDS can be cured or not is what they are most concerned about. Children are overwhelmed with the fact that '*many people in my village were infected with a strange illness which is incurable. Even if they spend a lot of money, the illness cannot be cured. A lot of people have died of this illness*'. They are worried a lot because of this. Zhao Yafang said: '*Dad is the only person who supports my family, but now he is infected with this illness [AIDS]. I can see that Dad is very tired when he does labour work. I feel sad every time when I look at him*'. One of the things that concern Ma Zhiqiang most is '*how long I can live, because many people in my village have died when they are younger than 30-40 years old*'. Li Mengxin said: '*I am worried about Mummy's health. I am also worried about whether my younger sister and I were infected with HIV, because I was born not long before Mummy sold her blood, and my younger sister was not yet born. I read the book someone gave to Mummy in which relevant things [mother to child transmission] are mentioned. My Daddy worries about my mummy's health. This illness has cost a lot of money. He goes to bed very late, often at 1 or 2 o'clock in the morning, but gets up at about 5 o'clock for work. At 1 o'clock after lunch, he needs to leave for work again. I also wonder whether AIDS can be cured if I am a doctor in the future*'.

The children have some knowledge about HIV/AIDS, but it is not comprehensive. For example, the parents of one of He Jinming's classmates are AIDS patients, and his younger sister is also an AIDS patient. I asked him why. He said because his classmate was born before his mother sold blood, therefore he has no illness.

From their descriptions, we can also learn something about the situation of the local AIDS epidemic. Zhao Yafang said, '*someone would die every few months in Shangyuan Village. I went there for an interview. My Grandma lives in Shangyuan Village. She is an AIDS patient. My Grandpa has lung cancer and oesophagus cancer. It is said that his illness is not because of AIDS but because he was surrounded by evil ghosts. He never sold his blood*'. She also said that people who are infected with this strange illness often feel scared, that almost all adults in my village have this illness, and even some children also have it: '*I am not afraid of the deaths because I know them [the people who died]. But people in other villages are scared*'. Zhu Xiaojing said, '*The situation in my village is the same. Many people have died since the 1990s, all because of blood selling. Several people die every year*'. Ma Zhiqiang said, '*many people in my village sold their blood, so they were infected with a strange illness. The patients become very thin and cannot do labour work*'.

According to our preliminary investigation, several areas in Fuyang including the Special Economic Zone, Funan County, Yingzhou County and some other places have been seriously affected by transmission of HIV/AIDS. Some children who took part in this research project were selected from these areas. The records of their interviews reflect a common experience, that many interviewees cried because of the sadness in their heart. In addition, through

this series of activities, we can see that because of HIV/AIDS, children who live in these areas are now facing serious impacts which are changing their daily lives and their expectations for the future.

(2) Worry that the family-patient will leave them

Most of the children who took part in these activities come from one-parent families. For some researchers, both their parents have passed away. They live with very old grandparents or other relatives. There are also many children among those who were researched who have lost one or both parents. Wangwei said in the summary of the research conclusion workshop: '*some of them lost one parent, and some lost both parents. For the children who lost one parent, their other parent has to migrate out for work, so they have to live with grandparents. For the children who lost both parents, they also have to live with grandparents. But how long can an old man live?*'

When we put the things that concern children most in order, we found that they were more concerned about their families' health than about studying and their future. Most children consider 'worry about families' health' as one of the five main concerns, together with concern about whether this illness can be cured. Because many patients have died, they also worry about whether their family members will die, thus leaving no one to raise them. Concern about health is also reflected in the wishes or desires of many children. For example, Hong Laisheng said: '*I wish my Mummy could be healthy earlier*'. Zhu Xiaojing said, '*I wish my Daddy could be healthy, I wish my family could be healthy and safe*'. Wangwei said, '*All of them want to have a happy home. But they sighed and said that is impossible. Some wish to be a doctor because the illness their families suffer from is incurable. They hope they can cure this illness and make everybody healthy*'.

When the children were defining which children are those who are vulnerable, facing difficulties, they highlighted children who have no parents (no home or families) as an important group. Orphans are facing difficulties because they have no one to look after them, love them and care for them, and because they have no source of money. Children who are from broken families are also facing difficulties, because they are lonely. They cannot feel happiness, and no one cares or helps them. Their studies are affected because of the distress caused by a broken family.

In the workshop activity about 'who can you tell your innermost thoughts to, and who can you ask for help when you are facing difficulty', we found that a family's situation has an unavoidable impact on children's minds. Parent's anxiety, worry and shortage of money have made these children worry also from a very young age. They cannot communicate their thoughts about this with parents or others. Many children who have lost one parent met a lot of difficulties but do not know who can help them. These children become more introverted, and more sensitive or thoughtful than other children. They also are not willing to disclose that their families are in difficult situations. There was a question in the interview schedule, 'Do you need help from others?' The results show that the number of children from areas affected by AIDS who answered yes is lower than those who live in families facing other difficulties. This is because of problems of stigma and discrimination.

Some children would go to the relatives who often help them if they have some innermost thoughts that they need to express, or if they need help. Some would ask their siblings for help (for example, one child said, '*I will tell my brother. Things like this can only be understood by him.*') Some would tell their close classmates. But there are still some children who cannot tell their thoughts to others. Take Qian Zhongfei as an example. His mother left him when he was still an infant. He has never seen his mother since then and he lives with his grandparents. His wish is to find his mother. Obviously, because he knows what has happened between his parents, it is hard to express this wish in front of his father's relatives.

One finding through our workshop activities is that many children who are facing difficulties, or who have some innermost thoughts, would ask for help from their teachers.

According to the children, teachers usually know a lot about their families. They also know whose parents have been infected with HIV or have AIDS, so the children can talk to the teachers if they have problems. For example, Xu Xinhe said, '*I would tell my teacher if I have some innermost words, because he/she can understand me*'. Zhou Shanghua said, '*Usually I would like to tell my innermost words to the person who understands me the most. This person is my teacher. She knows my situation. We have come to know and communicate with each other very well, so I will tell her my innermost words*'.

As to the answer to the question 'what will you do when you meet some problems you cannot solve?', the rate of children who will ask teachers for help with problems related to studying is 62.4%, and the rate of children who will ask teachers for help with problems not related to study is 42.9%. We also found that teachers play an important role in providing psychosocial support when children meet some difficulties. Teachers loom large in the mind of the children. Many children ask teachers for help when they meet problems. Some children are also concerned about teachers' health.

(3) Worry that others will look down upon them

When we held these workshop activities, we did not mention the topic of AIDS, because of issues of stigma and discrimination. It was, however, mentioned by children themselves when they introduced the difficulties in their villages, during the activities of the first and second weekends. We suggested children use 'children facing difficulties' instead of 'AIDS affected children' in the interview. Children broadly defined vulnerable children or 'children facing difficulties', which included children who have been orphaned, children who have dropped out from school, children without care, children who are frustrated, children who live in poverty, children who do not have good marks, children who are beaten by others and so on (see above, chapter four). We were afraid that some children who come from areas not affected by AIDS may become scared of or isolated from the other children if

we emphasised the issue of AIDS, hence the encouragement of a more broad definition.

During the workshop activities, we found that it was not an unnecessary concern of ours to avoid talking directly about AIDS. But after one-month of research, it was evident that children were much more worried about discrimination than they openly admitted. They thought that it is shameful to be infected with HIV. For example, one girl, Li Mengxin talked openly about AIDS in the first and second activities. But when discussing her interviewees and their families, she only said there are some patients in those families but never mentioned what the illness was. She only told us it was AIDS when we asked her privately. He Jinming and Zhou Shanghua were the same, only saying that people in their families were ill when we shared the photos. We asked them what the illness is and they answered, '*I don't know*' or '*it is a shameful illness*'. When we asked them this question again privately, they said it is AIDS. Jin Ming wrote on his hand to tell us secretly that it is 'AIDS'. The children all think that AIDS cannot be spoken about loudly because it is a shameful illness. Many children felt ashamed or dared not to discuss openly, although they know the truth and they also know others are in the same situation.

From the visits to villages to support children in their research, we know that less discrimination exists in those villages where most people are infected with HIV, because they think it is only due to blood transmission, teachers and schoolmates do not discriminate against these children. They still, however, think it is shameful to say or to write down. In some areas, discrimination is a serious problem. For example, in the activity 'who you can tell your innermost words', Li Mengxin said, '*I want to tell other friends not to discriminate against children who are affected by AIDS and to treat the children who orphaned because of AIDS better. I also want to tell people around me that shaking hands cannot transmit HIV*'.

When we spoke with some university students and some officials, we found that the awareness around AIDS is still low in Fuyang. Only advocacy activities on modes of transmission have been held. They do not know that

AIDS is not very distant from them. They lack understanding of the background and reasons for AIDS transmission. Some people hate those who sold their blood. They think it is their own fault they are infected and that it is unreasonable for them to ask for help, because they were 'too lazy' to work and made money only through selling blood. The suspicions linger also because AIDS is associated with 'immoral' activities such as sex and drug use.

(4) Afraid of having no food

There is a complex and close relationship between AIDS and poverty in this area. Poverty is the reason people sold blood, and they became infected as a result. They are now caught in a double bind: on the one hand, people with HIV spend a lot of money on medicine, but on the other hand, they cannot work to earn it. Both these factors exacerbate their poverty. What children are most concerned about is related to this. They worry about food (especially in one area because agricultural fields were redeveloped as economic/ industrial zones by government). They worry whether their villages can get out of poverty. They worry about food and clothes because they have no money. They worry about whether the food they have now is enough. They worry about how long their squalid houses can exist. They also worry about the money for treatment.

According to children's discussions, except for AIDS, poverty is main problem and the most difficult thing in villages. Poverty is reflected in some facts such as '*squalid houses, children dropping out of school*' (Fengtai Village), '*parents' migration for making money*' (Kaiyuan, Fengqiao Village), '*bumpy roads, non-harvest of crops*' (You Village, Qinghe), '*no tuition-fee*' (most children), '*no good hospitals and schools*' (Linquan County), '*no money for treatment and living*' (Zhongyuan Village), '*now people live a hard life, because they have no agriculture fields, they need to borrow any money they need*' (Special Economic Zone), '*due to the problem of money, parents migrate outside to make money*' (Yingshang County).

In the workshop activity for sharing photos, Wu Yuwei mentioned that some poor children have begun to make a little money to buy materials for school and to support their families. For example, they sell some recycling rubbish for money. Poverty causes many children to face the danger of dropping out from school and migrating outside for work. Some elder siblings of these 28 children had already migrated outside for work at the age of 16 or 17 years. Many children expect they can be independent one day. In fact some of them already are independent. They have begun to do housework. They also hope they can begin to make money for the family earlier. Poverty is the root of much high-risk behaviour, such as unplanned migration, illegal employment and not having enough knowledge and skills for work.

(5) Worry they may drop out from school

The reasons as mentioned by children for dropping out from school are the following: no money, having patients in the family, and responsibility for looking after families. Almost every child considers 'dropping out from school' and 'no money for tuition' as problems they are most concerned about. Education for them is not only an opportunity to learn knowledge, but also a preparation for work. If they cannot get a good score, they will have a greater possibility of dropping out from school, or of being looked down upon by teachers and schoolmates, and also they feel guilty towards their parents. Nearly half of the children think that it will be easier to find a job if they receive education. The remainder think that education can prevent them from having to take manual labour jobs in the future. Thus, they can support themselves and their parents. Education also can take them away from hardship and discrimination. They feel a person cannot find a job if he/she has never received education. Children also defined the children who cannot have money for tuition as being vulnerable, because these children may not find a job if they do not receive an education.

The conclusion to the question 'what kind of impact on children will the family difficulties cause?' was as follows:

40.5% of children thought that their studying would be affected; 12.6% of children thought that they will no longer receive money for tuition; 4.2% of children thought that they will lose confidence of living. Wang Wei said in his summary report, '*some people are infected with an incurable disease. Money was spent out for treatment. Sometimes they have large debts. Finally, the illness was not cured, and the family became poorer and poorer. Poor health makes them unable to do labour work. Children cannot make achievements in study because of distress for their families' poor health, so at last they have to give up school*'.

Besides having no money for tuition, the other reason why they drop out from school is they have to take responsibilities to look after the patients in the families and to do housework. In the activity 'one day of mine', some six children mentioned that they need to do housework and other work, such as cooking, feeding pigs and so on. It is girls especially who need to do more housework to help mothers. For those girls who have lost mothers, they need to do all of the housework. Usually they get up at 5 or 6 o'clock in the morning to cook for the whole family, and then go to school.

Responses

In addition to learning what children are most concerned about, we also learned about the most difficult things in their villages and what kind of help and suggestions they need. This was also a part of the questions in the interview schedules, and the workshop discussions here are included as part of the concluding chapter.

Li lives in our village, when I interviewed her she looked very nervous. Her family is very poor and her mother is so seriously ill that she can only lie in the bed. She looked very thin and terrible. When I asked her some questions her tears were falling down. She is in the first grade at high school and because there is no money her elder brother had to drop out of school. She cried and said if he doesn't go to school he cannot be an able person. During the days of my interview her mother was seriously ill and only had little meals. Her father, brother and grandma were all looking after her mother, even in the evenings. Her mother was so sick that she couldn't get up and needed someone to support her with their hands otherwise she would fall down. Her family is in an extremely difficult situation. During my interview her father got me to take a photograph of the mother, and on the second day when Li went to school, I also took a photograph of her brother.

---

6. THE FORUM ISSUES AND BENEFITS FOR CHILDREN

The forum raised two sets of issues. First, those from children, presented largely through dramas and drawings. Second, the forum further highlighted the benefits of the participatory and supportive processes of work with children, which had been already demonstrated through the whole series of workshop sessions.

The processes of the forum included different groups of children meeting each other, artwork, drama and discussion, and sharing of ideas and experiences. The presentation session itself was an immensely moving experience for all concerned, because of the powerful emotions displayed in the telling of stories. The forum was attended by senior local government officials, from several departments.

I heard the interviewee's miserable story, and I am thinking that to a human being except eating, drinking, playing and being happy, is there anything else? Some one are easy to get disease and they are very sick, for example some one affected HIV/AIDS. Many diseases, even my parents have got this disease which is very difficult to cure.

I know I am not a good talker but I want to add one point. That is when I talked about Ping, I have not spoken clearly, let me explain it again. Her family had been very happy but at the end her father died of a blood-selling disease and she is now living with his grandparents and her mother. Her mother goes downtown every day to do some labour work at a building site, she could only depend on her mother now.

Children's Forum Issues

Children's dramas focussed on significant events in their lives, and a dominant theme was stigma and discrimination. The content of the six dramas or presentations, in brief, was as follows. The first four were performed by children affected by HIV/AIDS and the last two by children from the small group homes. The sequence is not the order of presentation at the forum meeting.

Blood-selling
A blood-buyer advertising his visit; a woman going and selling her blood; she later finds she is infected with HIV; she goes to find the blood-buyer who pushes her away and disappears.

Children working
A boy lives with his grandparents and cannot afford to attend school. He works scavenging and begging during the day to earn money to attend school. But the family has no other income and so he must continue to work and has no time to go to school. He begs from cars, sitting in the middle of the road.

Discrimination against infected adults
A woman sells blood and becomes infected with HIV. Later she has no money and goes to the shop to ask for goods on credit. She is refused. No one else will lend her money, and they do not want her to come into their homes, because she is infected with HIV.

Study or work?
A young boy wants to leave school and migrate for work in order to help support the family through earning additional income. His brother has already gone and he wants to follow him. His parents say he should stay and study hard, but he puts family first and is prepared to go.

Children's discrimination against orphans
The young daughter protests at her parents' decision to become houseparents in a small group home for five orphans, because she does not want those children there. She is rude to the children. Later, she changes her mind and welcomes them.

Children's discrimination and bullying

In a school, as soon as the teacher leaves the classroom, the children bully and beat a child from the welfare home who is also disabled.

The Forum Event

Throughout the forum presentations, stigma and discrimination and their practical effects were a key theme. Also portrayed were the importance of family and the difficulties of survival and poverty. The dramas were more complex than these outlines indicate, and raised a number of issues. The whole process was highly emotional because of the complexity and the feeling for the circumstances portrayed. Nearly everyone present shed tears, and there was a tremendous experience of collective outpouring of grief, along with a sense of communal support simply in being together and part of this. The emotional content of the event cannot be ignored in any attempt to formulate an 'objective' or 'academic' research report. The process of the forum demonstrated the importance and benefits of qualitative research, the difficulties of objectivity in research and the need to recognise the personal. Most importantly, the forum highlighted and demonstrated what was already evident in the workshop sessions: the benefits of this way of working for children who are vulnerable or living in difficult circumstances. The project was not merely research, but already an intervention into the lives of some vulnerable children.

Benefits from Participation in the Process

Thus, an unintended result from the forum was an expression of communal grief for the death of parents and their situation, and following on from presentation of feelings of separation and exclusion, the problems of bullying, stigma and discrimination, and the difficulties of making a living. But children supported each other and there was mutual support between them and the adult facilitators. The outcome of the forum was also the fruit of the processes of work undertaken throughout the research, where children were taken seriously and adults demonstrated a willingness to listen to their concerns and an interest in their lives. Children responded through becoming lively and expressive, but also in forming new friendships, and in seeking out adults with whom to share their problems and concerns.

These children may meet more difficulties and more concerns than other children of the same age in other situations in China. Our workshop activities apparently provided them with an opportunity and a platform for help and support, in addition to self-expression and self-development. They all looked forward to the next activity. Some children have begun to keep in touch with each other after the activities by writing. When they took part in weekend activities, all based in the same hotel, some children gathered in one room to talk together for a long time. Adult facilitators and also adult visitors from outside noticed more and more smiles on the children's faces.

Part of the process of groupwork required that some issues raised by individual children could not always be followed up immediately in the public sessions for reasons of sensitivity and respecting children. However, since all participants, children and adults, were staying together in one place, children were able to approach adults outside group sessions to talk about their lives and problems. In addition, the children supported each other and talked a lot together. In this way the project was more than simply research or consultation, but provided mutual support and understanding, and this happened because of the fundamental principles of the work and because the project was essentially focused on children's participation. Adult-child relationships were crucial to the process of work in the project, but many (if not all) children were not used to adults spending time with them and listening to them and taking them seriously, the processes which created an environment that proved beneficial for providing support. Furthermore, the project brought together small groups of children who did not know each other at all beforehand, and so they also had to develop new relationships and the environment also needed to facilitate this.

Thus, all these elements of work are important as a

practical aspect of the psycho-social support that is so often identified as a need for children affected by HIV/AIDS, but not always discussed how to be achieved, save through face- to- face counselling sessions (see West 2005a). It is clear that forms of social support are imperative as a first step in providing psycho-social support.

From the children's feedback gathered up to now, we know that the children were very enthusiastic about the variety of weekend activities. Though some children did not like being a 'little journalist' (they were concerned about interviewing others who are facing difficulties), most children had a great interest in activities held over weekends in the hotel. The adult facilitators did not emphasise the issue of AIDS nor make basic knowledge of AIDS as the main content of the workshop. Children who have been affected by AIDS and children who come from other difficult family situations mixed naturally with no distance between them. They became good friends. In their evaluation, most children said they are very happy, and that through this activity, they have made many good friends, that they can communicate their innermost thoughts with others, and that they have broadened their vision. They hoped that activities like this can be held in the future. Some children wrote letters to others because they want to meet each other again.

For example, one child explained how she liked the activities, especially it seems, because she had little chance otherwise to find social support: '*I hope we could do some activity, play games together just like before. We could have less games and more activities* [discussions, drawings etc] *as such activity is very good and make us relaxed and do not feel pressure. I don't … [have much time] … because I need to have tuition on Saturday, and on Sunday I have to go back home washing my clothes and taking care of my grandma. In the Sunday afternoon, I also need to have tuition, so the time is very limited.*' The children enjoyed the activities because of making and being with friends: '*I like this activity very much, I hope we can keep on holding this activity, and I want to be a little journalist again, because it gives me a lot of fun.*' '*I hope you could help more poor people and we will have such activity in the future. I hope I could make more friends, and*

could see you again. I also hope to be a little journalist again. My suggestion is you could ask more children to answer questions and it will encourage them.' '*I hope we could make new friends, including: little children, young people, and adults.*' '*I hope I could meet my friends here during holiday, I hope we could help those children in difficulty and I could come again to participate activities like this, and will be happy like now.*' '*We could have more activities and we should care about and help those poor children.*'

Resilience

The research work, workshops and the children's forum also demonstrated children's resilience, which has been defined as the potential of these children to endure and flourish 'despite extremely challenging and stressful family and social circumstances including, for example, emotionally incapacitated parents and extreme poverty' (Duncan and Arnston 2004: 10). Some identified characteristics of such children include strong attachment to caring adults and/ or peer groups, encouraging role models, socially competent at interacting with adults and children, plays actively, curious and explores the environment, and others (Duncan and Arnston 2004: 10, adapted from the work of Donahu-Colletta). Many, if not all of these listed characteristics are aspects that were developed during this project work (although not intentionally with this in mind at that time). The workshops and research provided a safe interactive social environment with newly met adults and children; the workshops involved play as well as discussion and some learning (a child reported, 'I … think this activity is very good, it not only increased our knowledge but also expanded our view'); the adult facilitators provided role models, and so on. It is the learning gained of the multiple benefits of these processes for children individually and socially that should inform work to be undertaken with orphans and children affected by HIV/AIDS in the future.

7. THE FUTURE – MAKING A RESPONSE

The lives of children here are structured around home (family), school (study) and community (friends). These three locations, places, are sites of relationships with other people and of formal and informal learning. In this project, children highlighted as being most important the relationship aspects rather than the place itself, and this finding must be a central feature in any intervention or response to their circumstances, needs and rights. Children in this research are clear that the people who matter most are their family, their peers (friends) and potentially their teacher. Children do not want to leave their villages. In terms of home, children are concerned for the survival and health of their family in a positive way. That is, they do not just want material survival nor minimum living standards, but their concerns include relationships within the family and particularly about problems of arguments, fights, and violence, including being beaten themselves.

School and study are a major feature in their lives, important both at the present time and because of the perceived benefits of study for the future. Access to school is seen as essential, as is having a good teacher. Children are concerned about the costs of attending school and particularly about pressures on doing well. One of the impacts of the HIV/AIDS epidemic in this area is that children are concerned they will lose their teacher from sickness or death. The importance of school for children affected by HIV/AIDS is more than getting an education, but concerns skills and opportunities for survival in the future, and a means of escaping the poverty and fate of parents.

The local and broader community is clearly important, as seen in children's fears for the survival of the villages and more especially their concerns for friendship. Children's main connections are with their peers, but their fears for village survival shows a concern for the survival of their social world, and worries about problems of change, that is, what will happen because of all these deaths. These fears can all be summarised in children's fear of exclusion – that is fear of loneliness, isolation, stigma and discrimination, as especially shown in children's ideas of what makes children vulnerable.

Vulnerability

The question of vulnerability was raised during the workshop, when discussing which children who are in difficult circumstances, perceptions of which children are vulnerable, in difficulties? Children articulated a set of views that were both causes and conditions of vulnerability, and thus the inverse of their ideas begins to indicate what children hold to be important for a secure life, or perhaps the basis for a potentially fulfilled life. These children may have identified some of these characteristics of vulnerability more easily than others might because of the impact of HIV/AIDS in their villages, but this does not diminish children's perceptions of what is important – indeed it highlights their views on what effect the epidemic is having. Some aspects of their view of vulnerability reflect a concern of children that seems to be general in China (as noted in other research), for example worries about education and study, but which here is exacerbated by HIV/AIDS - as the children demonstrated.

The elements that make children vulnerable can be listed under four headings. Three of them - family, school (study), community (friendships) - can be linked together. The fourth element is children being lonely, isolated, where no one cares for the child, and they have no friends. This fourth is extended to include no family, home or relatives, and even the effect of a broken family, that is when parents separate or divorce (which might also include domestic violence, since this is a concern of children). Although poverty might be suggested as playing a part in these elements, for example in access to school, it is the emotional or mental health issues that children are emphasising rather than the material, as being the main problems that make children vulnerable. Factors that link – or are common to - the elements of family, school, community are: issues of beating or bullying by parents, other family members, teachers, and peers; and a fear of stigma and discrimination that stems from being part of a family with a member infected by HIV.

Impact of HIV/AIDS

The impact of HIV/AIDS disrupts children's lives and transforms their usual issues and concerns. Family and study remain areas of priority but the questions of health, and worry about the future are drawn in as more over-riding areas. It is not the family itself but the health of parents and other family members, and health of other significant people such as teachers, that becomes of major concern. This then is seen in the context of the viability of the family and its survival, and domestic tensions and relationships take on additional meanings. Thus, it seems that physical health of close family members has taken over as a main concern of children, including the health of grandparents and siblings. As noted by one adult facilitator, '*According to Chinese culture, the family is the basic unit in society. Family is also the place that will or should provide protection to children. If the protection or survival of the family unit itself is in danger, then some alternative is needed for these children, so they can still live a normal life under the protection of extended or adopted family. In addition, we should pay attention to solve the specific psychosocial problems faced by children affected by AIDS*'.

Similarly, the question of study might be expected to be important, given its centrality in children's lives across China, but it takes on a different meaning here. The new fragility of family and of community in these HIV/AIDS affected areas provides a greater urgency for study and doing well, in the context of children's future life and aspirations, and to provide for family in the near future. Children also recognise that they may need to be able to live independently earlier than expected, and so study is seen as essential towards a means of earning a living. Although older children have been migrating out in the past few years, the possibility of delaying this and studying more is diminished through the impact of HIV/AIDS using up family resources, often precluding parents earning income, perhaps requiring children to be involved in domestic work or even waged labour and so preventing their study.

All of these concerns that were initially outlined by the core group of children, were taken a stage further in the results of children speaking to their peers and collecting their views. Following their research, the problem of AIDS was brought out explicitly as the problem – and the question of whether it can be cured, raised by children in their analysis, may also be seen as related to the question of whether the equilibrium of family, village situation and relationships can be restored.

Worries and Fears: Isolation and Insecurity

There appears a shift towards a more cataclysmic tragedy in the minds of children, which is perhaps not surprising given the frequency of funerals and the overheard conversations that children reported which mean they sometimes can only surmise what is happening. So the fear that AIDS cannot be cured and the situation not changed is also a reflection that the situation is out of control, unlike perceptions of other sicknesses from which people recover. A number of children expressed a wish to become doctors, and hospitals featured in their drawings, indicating how much medical attention was part of their lives and their desire to understand more. For example children said that there is '…*no good hospital. Some people who were infected with this illness* [AIDS] *cannot be cured*' (Fengtai village), '*health, now some people are infected with an incurable disease. They have no capacity to maintain their life. Their life is hard*' (Special Economic Zone). In their narratives the question of cure is central because without it, AIDS may cause problems, such as people dying when they are still young, people's ability to do hard labour is reduced, all the money is spent, poverty is exacerbated, children drop out from school, and some children are orphaned without care. Children also said the fact that there is no good hospital and no excellent doctors in the village is also a difficulty, which may also be why children see curing this disease as a most important factor in solving the difficulties: that is, there is currently no cure available locally.

Following on in the sequence of children's fears, if AIDS cannot be cured then that exacerbates other worries: that

parents and other family members will die; that children will be left behind but looked down upon and isolated; that children will have no food. Finally, the fear that children will drop out of school, the only area left with any hope of 'normalcy'. After family is gone and community has disintegrated and/ or excluded children, their one remaining hope for the future is to study – but if they drop out this will be impossible.

This 'cataclysmic' view is logical and fits together, especially when the usual experiences of children are considered. Family is very important in many societies and particularly so in Chinese culture. Traditional ideas of hierarchies within the family privilege the roles and ideas of adults over children, and link them to the chain of ancestors stretching into the past. The rules of behaviour within the family are promulgated by adults and elders, just as the rules of how the local community operates stem from them. Adult teachers run the school, but children need peers for company and in helping to make sense of what is happening. The problem with AIDS is that, unlike other health problems, it appears to be beyond the control of adults. But because children are generally not party to adult discussions, and only overhear some conversations and events, they do not know exactly what is happening. AIDS is not publicly discussed, and there is fear about disclosure of even having been tested, let alone being positive. The uncertainty about the present also feeds the problem of uncertainty for the future, and an awareness of the possibility of exclusion, isolation, loneliness and emotional upset.

Because of the problems of stigma and discrimination, children have to deal with this by keeping quiet about it and carrying their worries with them. They cannot openly discuss their family problems or feelings. When such an opportunity does arise, as in the forum, the emotional outpouring and communal grief is tremendously powerful, and points to a central requirement for any intervention: the need to work not only with (alongside) children but in particular ways to retain their sense of stability whilst enabling change to be recognised and grief expressed.

Finally, the research raises important issues for the care and welfare of orphans. At the centre of children's issues is a concern for stability and security in a set of crucial relationships which also contribute to their identity, their sense of self: family, friends and teacher. Removal of children to large orphanages usually destroys these relationships, because children are placed where it is convenient for adults, where there are vacancies. They are often separated from remaining family members, who they then see rarely, if at all, and separated from friends. They may have to sing praises for visitors in order to solicit donations and so diminish their sense of self. They may not be able to attend their familiar school, and even if they do, their identity, their status is changed, and they may experience discrimination and bullying. The importance of school and a family setting is seen in that some children suggested that people could adopt orphans and help children go back to school if necessary.

WHAT IS TO BE DONE?

Children said that they don't want to leave their village. Children remaining in a familiar, identifiable community, with friends, attending school and maintaining family relationships is a primary aim, with the eradication of stigma and discrimination, and provision of social activities and support, and community networks as key objectives. This may be done by recognising children's actual and potential resilience through their participation in decision making in a safe environment. Because of the current experiences of exclusion of some children, and the need to provide support to children through processes of separation and loss, children's activity centres, properly facilitated with a central component of children's participation, can be developed, around which can be built a range of projects to address their concerns, from skill training to treatment, and especially as a point from which to address problems of prejudice, stigma and discrimination.

The project overall, workshops and forum, found that creating child-friendly environments, taking children seriously, listening to children, reflecting their ideas and views, encouraging children to communicate their

experiences and feelings, all provide support, develop children's self-esteem and confidence, support children's learning, enhance children's capacities in forming relationships and communication, and most importantly, act as a conduit for children's emotions in enabling their self-expression. These approaches can be taken further and sustained over a longer period. Thus, principles for developing provision must include:

· recognising children's actual and potential resilience through their participation in decision making in a safe environment; and

· multi-sectoral and multi-agency working that is necessary to achieve the flexibility of services (including education) required, given that poverty cannot be eradicated overnight.

Children's Activity Centres and Psycho-social Support

This project has demonstrated how 'psycho-social support' for children can be provided in practice. That simple, genuine, honest interactions between adults and children, and facilitating activities between children on principles of treating each other with respect, provide substantial bonds of support. Such interactions can be provided on a regular basis through children run and led centres, as shown elsewhere in China (see West 2004, and Save the Children's work in Anhui, Yunnan and Tibet for examples). The provision of social activity centres is a means of providing the crucial social support that children need in order to combat feelings and experiences of isolation and exclusion.

Overcoming stigma and discrimination requires children's experiencing that they are valued and respected as human beings and do have some place in the social world. Their fear of isolation needs facilitation of social links and friends, enabling them to attend school and retain their self-esteem. Children's activity centres provide a practical means for facilitating social links. Such social links and networks are a means of supporting children through bereavement.

Children's activity centres can also provide spaces and opportunities to facilitate peer support, and offer provision of advice, information and guidance for children. They can be bases for informal education, including lifeskills, proper preparation and consideration of migration and work opportunities, vocational skills training.

The use of children's activity centres, properly facilitated with a central component of children's participation, can be a major starting point in responding to children's circumstances. In practice, such work with children could be the key for future programme intervention, raising and advocating children's issues, and around this can be built a range of projects, from skill training in care and HIV/AIDS prevention to treatment. These places are also one point from which to address problems of prejudice, stigma and discrimination that are especially significant in children's lives.

Family Health and Support

Parents infected by HIV ultimately may not be able to be kept from death, but a feature of programme work should be that they are kept alive in good health as long as possible. This means not only medical treatment but social support, and especially not leaving the burden of care to fall on their children, or parents. Supporting children in care for parents and other family members, is complicated given the needs of cooking, housework and ensuring children are able to attend school. Networked community support mechanisms are needed. Another use of local centres is that they can be focal points for such networking, for the development of volunteer services and for training in care skills. Some general poverty alleviation to enable children to study, prevent early migration and for costs of medical treatment will be necessary.

HIV/AIDS, Stigma and Discrimination

Training and programmes to prevent HIV/AIDS transmission must be linked to the programmes to eradicate stigma and discrimination which are essential. For children these might include peer learning, but an important focus must be school. General anti-bullying campaigns and work in school is necessary which will help create child-friendly environments that are beneficial

to learning, but will also begin to tackle cultures where stigma and discrimination breed. Teachers and all school staff need to be trained in HIV/AIDS awareness and prevention, and anti-discriminatory practice in means of dealing with bullying and prejudice.

Orphans

Support for orphans to remain in their home communities will require practical financial support as appropriate, provision of skill training, advice and information, social activities. Children suggested that orphans be locally adopted or fostered, and this would also require support. There should also be recognition that households headed by older children are a viable proposition, especially given appropriate local support, perhaps through a local centre or regular visits. Older children already have responsibilities and often migrate out for work

Training for Staff and Volunteers

The effective implementation of children's centres will require adult facilitators for their initiation and in providing support to children and to parents and others. This means that adults require training in skills of participatory work with children, in addition to a range of other issues, in particular in preventing HIV/AIDS transmission, anti-bullying and anti-stigma and discrimination work and support. Adults will have roles of facilitation, listening, mentoring, advising and need competence (skills, knowledge and understanding) to do this. The development of a network of volunteers is the development of local community workers, but who have child-focussed participatory practice at their heart.

Access to healthcare and education

Children's participation and protection are core elements of practice, but work on access to education and healthcare will be necessary alongside and in association with combating discrimination and developing networks of support.

Integrating Provision

The development of services and facilities needs local cordination and monitoring: Different agencies and government departmentshave to be included and provision must be integrated to be effective. Children should be fully and actively involved in consultation and decision making with children's and young people's representation.

━━━━━━━━━━━━━━━━━

From all the interviews Di gave me the deepest impression. Her family are very poor and their house is very small and dilapidated but she never showed any feelings of inferiority. She works hard and is the top student in her class and the teacher often praises her. I also took a photograph of her house. You will think it is very shabby when you see it. I believe children from poor families can also make great achievements. If only we could follow the example of Di and study hard, we could become the backbone of our country.

━━━━━━━━━━━━━━━━━

REFERENCES

Anhui Daily 2003 'With the number of infected cases being 1558 and deaths being 186, the situation of AIDS prevention and treatment in Anhui Province is serious' *Anhui Daily*, 2nd December 2003

CCTV 2003 CCTV International www.cctv.com/international November 2003

China AIDS/children 2004 '"AIDS and Children" focus hotspot' China Children Information Web http://www.cinfo.com.cn/rdjj/001.htm access 2004

Danziger, R. 2000 'The Social Impact of HIV/AIDS in Developing Countries' in *Readings in the Sociology of AIDS*

Duncan, J. and Arnston, L. 2004 *Children in Crisis: Good Practices in Evaluating Psychosocial Programming* USA, Save the Children Federation, Inc

Framework 2004 *The Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS* New York: UNAIDS, UNICEF, and others

Ji Gouping 2003 'Report on First Business Visit to Fuyang' and 'Report on the HIV/AIDS KAP survey in Funan County, Fuyang, Anhui' Hefei: Save the Children internal reports

Joint Assessment Report 2003 - State Council AIDS Working Committee in China, UN Theme Group on HIV/AIDS in China, Representing the ten cosponsors of UNAIDS, *A Joint Assessment of HIV/AIDS Prevention, Treatment and Care in China* (2003) Beijing: Health Ministry of China

MoCA (Ministry of Civil Affairs) 2003 'Children In Residential Care In China' presentation for Stockholm conference, 12-15 May 2003

MoCA (Ministry of Civil Affairs) 2004 *Statistical Yearbook* Beijing: Ministry of Civil Affairs

Phoenix Weekly 2003 'The Situation of Several Thousands of Children Orphaned because of AIDS in Henan Province' *Phoenix Weekly* 15 (2003), p12- 16

SC CPN 2003 Save the Children China Programme Newsletter, Number 20 parts one and two, 'Children in Care' and 'HIV/AIDS Prevention' Kunming and Beijing: Save the Children UK

Voices 2003 'The Situation of Children Orphaned because of AIDS in China attracts attention' *Chinese Voices* newspaper

West, A. 2003a 'Children in Care and Researching Standards' *China Social Welfare Journal*

West, A. 2003b 'Participation, Rights and Children in Care' *China Social Welfare Journal* October 2003

West, A. 2004 'Centres and Hubs: a focus for developing children's participation and child protection in China' first version, Kunming: Save the Children discussion paper

West, A. 2005a 'First Of All … The Social Part Of Psycho-Social Support: psycho-social support, participation, protection and social activities for orphans and children affected by HIV/AIDS' paper for the 'National AIDS Orphans Psychological Care training', Shanxi, March 2005

West, A. 2005b 'Children's voices, views and participation in China' (provisional title) Beijing: Save the Children, forthcoming

West, A. and Wedgwood, K. 2004 'Children Affected By Aids, Orphans, and Impact Mitigation In China' paper presented at the Third Asia Public Policy Workshop and the Fourth WHR Rivers Symposium 'Social Development, Social Policy and HIVAIDS in China' at Harvard University, 6th – 8th May 2004

Zeng, Z., Yang H.Y., West A. (eds)2004 *Child Participation in action; Concepts and Practice from West to East*, Beijing: China Legal System Publishing

a strange illness

issues and research by children affected by HIV/AIDS in central China

'There is a strange, horrific, illness.'

'Children publicly call it a blood selling strange disease or illness. When you get to know them well they will tell you it is AIDS. One boy wrote HIV/AIDS on his hand and showed it to us discretely, only because of his worry about discrimination and stigma. Children know that when people know a family member is infected with HIV, the whole family is affected, and that they cannot find a job in the future and no one will want to marry them.'

'a strange illness…' is a report of issues and concerns raised by orphans and children affected by HIV/AIDS in an area of central China with a severe HIV/AIDS epidemic. This project was undertaken as a preliminary study for a longer programme of child-focussed work in the area to provide care, support and treatment within a framework of child protection and children's participation. The main findings of the project relate to children's experiences and potential for exclusion, loneliness, isolation, uncertainties and their corresponding fears and worries for now and for the future. Children are most concerned about tensions and health within their family, friendships, stigma and discrimination, survival and the future of their families and themselves, and study – going to school and performing well. The feedback from children involved in the project show how the methods and activities used, including the approaches of taking children seriously, having fun, treating children with respect - participatory ways of working with children - were found to demonstrate and provide psycho-social support and personal development, and promote resilience.

Save the Children works to create a better world for children. Our mandate is the fulfilment of children's rights - the right of all children to be listened to and respected and to enjoy a happy, healthy and secure childhood that supports their development. We work in many provinces across China, cooperating with different levels of government departments and communities. With offices in Beijing, Anhui, Yunnan, Tibet and Xinjiang, we work with partners in health, education, protection and welfare, focusing on particularly vulnerable children, such as street children, disabled children, trafficked children, minority children, children in conflict with law and migrant children. In all our projects participatory and integrative approaches are used to develop and promote new ways of working, and influence policy affecting children. We learn from each other, plan, create and make decisions together. In all our work, Save the Children strives to achieve real and lasting benefits in children's lives.

Fuyang Women's and Children's Working Committee

Save the Children