



Best Practices

Care and Support to Children Affected by AIDS

UNTG on Children and AIDS

June 2009

UNITE FOR CHILDREN
UNITE AGAINST AIDS



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INTRODUCTION

The “Unite for Children, Unite against AIDS” Global Campaign was initiated by the UN in November, 2005. With great attention to children and AIDS, the Government of China launched the Chinese Campaign on Children and AIDS in September, 2006. To facilitate experience sharing on the campaign among UN agencies, NGOs and bilateral and civil society organizations and boost their participation, the Children and AIDS Working Group of the United Nations Theme Group (UNTG) on AIDS made a collection of best practices on PMTCT, treatment and care for women and children with HIV, vulnerability reduction for youth and stigma reduction in the hope that the documentation contributes to experience and expertise sharing aiming at tailored interventions to meet the needs of target populations.

DISCLAIMER

Agencies contributed to this documentation on a voluntary basis. UNICEF as the editor is not responsible for the accuracy, completeness, or usefulness of any information disclosed or the legitimacy of any agencies or organizations. The response by the Chinese Government to the issue of children and AIDS and information on the Chinese Children and AIDS Campaign are released by the State Council AIDS Working Committee Office (SCAWCO) annually and not included here. The single purpose of the documentation is to facilitate information sharing within the Children and AIDS Working Group of UNTG on AIDS.

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PROTECTION, CARE AND SUPPORT

CHILDREN AFFECTED BY AIDS

The terms ‘children affected by AIDS’ and ‘affected children’ refer to children and adolescents under 18 years old who: 1) are living with HIV, 2) have lost one or both parents to AIDS and 3) are vulnerable, i.e. children whose survival, development and well-being are threatened or altered by the epidemic.

The protection of children affected by AIDS requires the strengthening of national and community-level responses for all vulnerable children. Governments and civil society organizations, as well as their partners, can make a huge difference towards this goal by enhancing social protection, legal protection and justice, and alternative care. This work must be underpinned by efforts to address the silence and stigma that allow HIV-related discrimination, abuse and exploitation of children to continue.

Enhanced Protection for Children Affected by AIDS
UNICEF

CHILDREN IN THE SHADOWS: A UNIQUE RESPONSE TO THE DEEPEST PSYCHOLOGICAL NEEDS OF ORPHANS AND VULNERABLE CHILDREN

A Comprehensive Program Providing Holistic Support to Orphans and Vulnerable Children

FXB

Janice Secord Neilson

This pilot project demonstrates that strategic community-based intervention can profoundly affect the lives of orphans and vulnerable children and the families that care for them. The 3-year project, launched in 2006, is driven by the belief that every child deserves to be loved, wanted and nurtured. The child is the primary client and in every decision, the needs of the child are paramount. The entire project is a holistic, comprehensive care program intervention. A mid term evaluation by Beijing Institute of Information and Control (BIIC) concludes “remarkable improvement” in quality of life for both orphans and vulnerable children affected by AIDS and the families that care for them.

This article focuses on one intervention of the model – a response to psychological and emotional needs of orphans and vulnerable children affected by HIV/AIDS in rural China. To the author’s knowledge, the combined elements of this psychological intervention are not present in any other program, anywhere.

WHO ARE THE CHILDREN?

The children are single or double orphans affected by HIV/AIDS and living in rural poverty. They suffer from depression, abandonment, grief and loss, post-traumatic stress and stigma and discrimination in their communities. In many cases they are living in an unstable family environment, and in some cases they are physically ill or living alone.

WHY IS THIS PROGRAMME UNIQUE?

Many programs provide nutrition, hygiene, access to education, healthcare, and income generating activities to assist families living in poverty. What sets this program apart is a unique response to deep psychological needs of orphaned and vulnerable children. Mid term evaluation data concludes that severe depression in children was reduced from 89% to 4.5% over 18 months, from the baseline to the mid term evaluation.

Over three years, the program provides nutrition, hygiene, access to health care and education, safe housing, **Child Life Planning and intensive psychosocial support**. In addition, committed caregivers receive income-generating activities (IGA).

During the first 18 months, the project teams counsel beneficiaries through constant home visits, and delivery of basic needs (food, clothing, bedding, basins, and hygiene articles). Children have physical exams, access to medical care, are enrolled in school, or vocational training. Urgent health needs of caregivers are addressed and unsafe homes are repaired. Caregivers receive Income Generating Activities (IGA) to improve the family economy. Together, these interventions begin to lift the anxiety of grinding poverty and open a window of hope.

With adequate nutrition, home repair, and the support of the project team in place, adult beneficiaries are strong enough to improve their economic self-sufficiency. Beneficiaries then choose an IGA activity, and the project team helps them to create an Economy Plan detailing how, with increased IGA income, the family can provide nutrition, health care and education for the beneficiary child at the end of the project. Families sign a contract agreeing that proceeds of the IGA will be used to pay for the needs of the child. As most families are illiterate, creative teaching and learning techniques are provided to ensure the understanding of the plan.

The final, and most important, pillar of the China Project combines **two strategic interventions** to meet the deepest psychological and emotional needs of these children. This takes place during the last 18 months of the project and is, other than food, seen as the most important intervention to improve their quality of life. The two interventions are:

- 1) **CHILD LIFE PLANNING**
- 2) **“I AM WHO” PROCESS**

“Before this program, we thought filling the stomach of our children was enough.” village leader, Yunnan Province

1) WHAT IS CHILD LIFE PLANNING?

Consistent with the UN Convention on the Rights of the Child, Child Life Planning recognizes the rights of a child to have a permanent, nurturing, stable caretaker and to know what his or her future is if that parent or caretaker is deceased or will be incapacitated in the near future. Child Life Planning recognizes the rights of parents, extended families and ethnic groups to make decisions about the care of their children. Child Life Planning is an intervention for children who do not have a family member, who is able or committed to care for them or will not have a caregiver in the near future due to sickness, incapacity, or other life events. Child Life Planning minimized the trauma of child abandonment and preserves family care giving relationships. The process reunites children with nuclear families, integrates children into extended families or facilitates formal legal custody or adoption by a family within the child's community.

CHILD LIFE PLANNING: BEST PRACTICES

Child Life Planning culminates in a legally enforceable written document that creates

rights and responsibilities with regard to the care, custody, decision making and support of a child in the event the parent or primary caretaker cannot act as a parent. It also creates duties for the child to comply with caretaker directives.

Minimum Requirements:

1. A decision by child's primary caretaker, in consultation with the child (if age appropriate,) the extended family and the ethnic community.
2. In writing, legally enforceable.
3. Respectful of ethnic culture and values.
4. Effective when parent or current primary caretaker is deceased or incapable, physically or mentally, of adequately caring for the child, or if the conditions will exist in the near future.
5. Recognizes rights of parents, extended family, and ethnic group to make decisions about care of their children.
6. Recognizes rights of the child to have a permanent, stable, good caretaker and to know what his/her future is if parent or caretaker is deceased or incapacitated.
7. Recognizes child's duty to follow parenting decision of caregivers.
8. Recognizes the rights of a child under applicable law, including rights to inheritance.
9. Must include the statement that it will be reevaluated by signatory' upon any major change of circumstance for the child or proposed caretaker, which interferes with the caretaker's ability to act as a parent. (example: death, mental illness, incarceration, physical injury)

Preferred placements in order of priority:

1. Birthparents
2. Immediate family who knows the child
3. Extended family
4. Ethnic group
5. Others

Preferred Legal Procedures in order of priority

1. Adoption (domestic)
2. Third Party Custody contract, agreement or decree approved by parents if available, family, court, civil affairs, ethnic groups, leadership, village elders which gives custodian rights to make all decisions about the child (health, education, etc).

Informal Agreements – Informal Agreements not containing the entire minimum contents are not acceptable as a Child Life Plan under internationally recognized best practices. Grant Funds cannot be spent to implement such a plan. Contracts must comply with local, provincial and national Laws.

Decision Making Standard:

All decisions in the Child Life Planning Process shall be made by answering the

question:

“WHAT IS IN THE CHILD’S BEST INTEREST?”

It must be recognized that the child’s best interest may be different than the interest of the parents, extended family or ethnic group. When the child’s rights conflict with others, the child’s rights must prevail.

When determining what is in the child’s best interest, all factors impacting rights and welfare of the child must be discussed including health, education, psychological welfare, nutrition, safety, right to be free from physical – sexual abuse, rights of inheritance, to be with siblings, in close geographic proximity to extended family members, to maintain healthy emotional bonds and relationships.

Any exception to Preferred Placements and preferred procedures must be explained in writing and signed by the person(s) making the decision. Example: the child shall not reside with Uncle X, because he is very sick, unstable, etc.

Family’s choice must be honoured unless good cause exists to not accept this decision. If family decision is not accepted by project authorities, no IGA grant funds are to follow the child.

Families who agree to accept custody and care of a child and sign adoption or custody agreements receive an incentive of an Income Generating Activity (IGA) (livestock, agriculture) worth approximately \$150.00.

HOW TO IMPLEMENT CHILD LIFE PLANNING: FAMILY GROUP CONFERENCE PROCEDURES

“This was a precious chance for us because we never before gathered together to talk about the future of the child.” – Aunt of the child after family group conference

Identify family members to be in Family Group Conference and invite as many family members as possible to attend.

Meet with the family at their first gathering meeting and identify possible alternative placements for the child. (Name, age, location, employment, relationship to child) example: (Wang, age 46, uncle, in star village, farmer). Does the child know the person? Is the person of good character to take custody of the child?

1. Invite all identified family resources to a meeting to discuss the FAMILY’S plan for the child.
 - A. Set up family group conference meeting at or near the child’s home.
 - B. Explain that project staffs are there only to facilitate discussion and decision. Authorities, government, project staff are not making the decision or trying to influence it.

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- C. At the meeting, project staff explains the purpose of the meeting and issues faced by the family (i.e. health, and child's need for permanency and a child life plan.) Explain what permanency means, what a third party custody agreement is and what it must contain.
 - D. Let the family take over the discussion. A leader will emerge from the group. Let them make a decision. Remind them that the standard is what is in the child's best interest, and that they should consider all factors which impact the child's life such as proximity to his school, friends, relatives, especially siblings, and the emotional ties he has to certain people. Child's safety is of most importance.
 - E. Project staff explains that if the family makes a decision that project staff does not think is in the child's best interest (i.e. child goes to unstable, abusive uncle), no project funds for IGA go to that person.
 - F. If the family makes a decision, it is briefly written down and all persons who participated (agreed to it) sign it. NOTE: it may take days or weeks for the family to agree to the decision; it may not occur at the first meeting. They may need to think about it. Families are told not to rush the decision and encouraged to have at least 2 or 3 meetings to make the final decision. The village leader is invited to attend the meetings, if the family chooses to do so.
 - G. Family and project staff decide how the child is told if the child did not participate in the decision. Usually the person informing the child should be the adult, who the child is nearest to emotionally.
 - H. Action plan to implement the decision is agreed to: 1) if it is adoption, which will go to civil affairs and when? 2) if it is third party custody agreement, who will write it, who takes it to get official approval by elder, ethnic group, court or civil affairs? Project staff should provide a sample for them to use and assist them in getting this done.
 - I. Beneficiary caregivers are provided an additional ½ IGA incentive (value of about \$150.00) when assuming care and custody of a child through the Family Group Conference process and after signing a Child Life Plan custody agreement approved by all parties and approved in writing by the local project authorities.

“We don’t mean that our children will compare with other children in clothes or food. But we need to keep our children in homes, in stable environments like others. That is what we need to do.”

- Village leader, Yunnan

2) WHAT IS “I AM WHO?”

The “I AM WHO?” book program is provided to each child, over a 12 month period, at the same time as the Child Life Planning process. Together, these two interventions address the deepest fears of orphans and vulnerable children: “Why did sad things happen in the past? What will happen to me in the future?”

The ongoing “I AM WHO?” program reaches children exactly where they are. Beneficiary children have lost parents to death and/or abandonment, are living in poverty and unstable conditions, and suffer from depression, anxiety, lack of

self-esteem, hopelessness and post-traumatic stress. The “I AM WHO?” process helps them to better understand the past, better cope with the present, and feel new hope for the future.

The “I AM WHO?” process encourages children to express feelings in a safe and nurturing environment. Through creative, playful activities, children explore issues of self-worth, identity, home, ethnicity, village, family background, history and customs. They preserve memories as they record and honour special people in their lives, play imagination games, paint and write while developing emotional awareness and expression. In later activities, they identify and practice meeting goals, and express hopes and dreams for the future. At the end of a year, each child has created a book about themselves which answers the question, “I AM WHO?”

Activities begin with a welcome to each individual child and warm-up activities. Singing is a favourite warm-up activity as it lifts the spirits of both children and adults and moves the mood to the theme of the day. Each activity, introducing one section of the book, includes music, movement or dance, art, writing, snacks and a positive message intended to build hope and confidence in children. Following the activity, an entry is made in the related section of the book: something created by the child, a photo and thoughts of the child on that day. Parents and caregivers are encouraged to attend so that they understand and support the process. As most are illiterate, many activities do not require literacy to participate. Caregivers are responsible for meeting the needs of children’s ongoing life and must understand and support the purpose of the activities.

It is best for children to work on one section of the book at a time and to complete the book over a year’s time, to allow for reflection, creativity and understanding. This also allows the teacher to introduce each section of the book, to carefully watch children’s comfort with the process, to involve family members to support children, and allows time for children to create, find or research information to start and complete the book.

“This painting makes me feel warm in my heart.” Girl, age 12

The activities are designed as playing and learning for groups of children, although they can also be used with one adult and one child. For working efficiency, the teacher can gather about 10 children together (for example, gather children of the same village or the neighbour villages together) to conduct the activities and repeat using the materials. The number of children should be limited to allow individual time and attention for each child.

Some subjects in the book are sensitive, such as reflecting on someone the children loved and have lost. Children must be comfortable all the time, offered the opportunity to express their feelings, allowed to move at their own pace. The activity will be presented, but children may choose to complete the activity or not. It is up to them. In the last activity, children will explore what they have learned in the “I AM WHO?” process and finally answer the theme question of their book, “I AM WHO?”

“I love this imagination game - the tender tiny tree is growing with no sorrow or sadness.” Boy, age 10

The “I AM WHO?” book is a possession of the child, and contains all activity information. Children have the option to complete any activity as they wish and are encouraged to add information to the book in the coming years. All information in the book is private, and may not be read by others without the child’s permission. The privacy of the child is respected at all times.

“I love the words here. It is my favourite part because it tells me what I should and can do tomorrow.” Girl, age 14

***“Whenever I open my “I AM WHO?” book,” I feel my father is close to me.”
Girl, age 15, whose father died recently***

PROJECT EVALUATION

From July 2006, supported by FXB China, supervised by Yunnan Women and Child Development Center (YWCDC) and implemented by the Luxi and Longchuan Women's Federations, “A Comprehensive Project Providing Holistic Support to Orphans and Vulnerable Children” began. Prior to the implementation, UNICEF, FXB-China, Beijing Institute of Information and Control (BIIC) and Harvard University together designed a child-centered questionnaire for the project’s baseline, mid-term and final evaluations.

Supported by UNICEF CHINA, The Beijing Institute for Information and Control is conducting a formal evaluation of the Yunnan Women and Child Development Center (YWCDC) projects in cooperation with the Luxi Women’s Federation and the Longchuan Women’s Federation.

The mid-term evaluation studied current beneficiary children who were evaluated in the baseline survey and contrasted the difference between the baseline and mid-term data of these children. In the analysis of the children’s psychological status, project activities are found to have “remarkably improved” the psychological status of the children, especially in the four aspects: developmental trend to the future, self-awareness of health, functionality/capacity, and internal/external behaviours. The report concludes that the project activities make the children happier, more confident, more open in character and having stronger hope and expectations for the future.

The lessons learned and suggestions of mid-term evaluation provide guidance for the remainder of the project.

IMPLEMENTATION

FXB-China is fortunate to partner with the Yunnan Women and Child Development

Center in implementation of the China programs in Yunnan Province and the Butuo Women's Federation in implementation of programs in Sichuan. Through them the project works closely with local administrative authorities who support the project, including the departments of health, education, livestock bureau, agricultural bureau, etc. The beneficiaries' selection process takes into account the degree of vulnerability of the children and members of a household, the economic situation and viability, the capacity and willingness to participate in the program.

The project has been developed through continual dialog with the local community, the local Women's Federation partners and adapted to the evolving context of HIV and AIDS policies and activities. The program remains closely embedded in the community and participants are directly involved in the choices and decisions concerning them.

The key strengths are the project management staffs in the Kunming YWCDC and the Luxi and Longchuan Women's Federation, along with local team members who provide constant in-home counselling and support to the beneficiaries. Team members are hired from the local community and represent the ethnicities of the beneficiaries. Each team has two social workers, a medical worker, and a driver. The remarkable diligence, creativity and commitment of these managers and teams make the project possible. Each project serves 100 children and their extended caregiving families (500 beneficiaries).

The strength, success and sustainability of the project come from the community itself. Participation by local beneficiaries in the design and implementation of the program is critical, particularly the placement of children in stable and loving homes.

OUTCOMES

- **A community based comprehensive care model which improves quality of life for AIDS affected children.**
- **A formal evaluation which substantiates lessons learned and outcomes in order to promote best practices.**
- **A cost-effective replicable model.**

The results of the project are plentiful in a community. After three years, the support and skills needed to provide its children with a safe and secure future have been increased. Over time, income generated activities, in combination with temporary assistance, become a sustainable means for households to earn a living and provide for children in their care.

Children and young people reap the long-term benefits of good health, participation in school or vocational training, security in a stable nurturing family, significantly increased self-esteem, confidence and hope for the future.

The model also leaves a legacy in skills and knowledge. Local Women's Federation staffs have integrated state-of-the-art international social work standards into their programs and are now experts in the area of Child Life Planning and psychological intervention through the "I AM WHO?" process.

The success of the model demonstrates that strategic and comprehensive investments can profoundly affect the lives of the children and communities severely influenced by AIDS.

A significant strength of the model lies in its long-term investment in the community at a relatively low expense. The program lasts three years and costs \$190,000 over that time frame, or about \$125.00 per beneficiary per year.

FXB-China is proud of its long-term collaboration with UNICEF-China and UNICEF Headquarters through whom we are guided and remain in touch with the latest global policy and practice developments.

CONCLUSION

Security is the most important factor influencing quality of life for a child. A child gains security from a stable nurturing family environment and the child's inner sense of safety, confidence, self-esteem and understanding of their life situation. **Together, the Child Life Plan and "I AM WHO?" activities provide this security to beneficiary children.**

This project is guided by the United Nations Convention on the Rights of the Child as adopted by laws of the Peoples Republic of China and accepted international child welfare best practices.

Notes:

- 1) The FXB China Pilot Project is separate and distinct from the FXB International Village model.
- 2) Child Life Planning is known as Permanency Planning in International Child Welfare practice. .

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PROVIDING QUALITY ESSENTIAL HEALTH SERVICES TO VULNERABLE CHILDREN AND MOTHERS

Save the Children

Providing Quality Essential Health Services to Vulnerable Children and Mothers (MCH project)

- Providing high-quality medical services to poor and marginalized children and women to reduce child mortality, improve women's health and prevent the spread of HIV and other infectious diseases.

Save the Children China Programme

1. Background

Dicheng Town, Funan County of Anhui Province, a town of 24,000 square kilometres with 7 administrative villages has a population of 34,000, including 8,071 women, 3,280 children and 45 people with HIV. Taozhai Village, an administrative village of the town, covers 23 natural villages and a population of 5,030, including 2,425 women, 1,200 children and 14 people with HIV. The village has 3 private clinics and 2 primary schools. The net per capita annual income is 1,930 RMB and primary school enrolment is 100%. A boom in blood selling in the early 1990s resulted in HIV infection among villagers, some of whom have developed AIDS. A lack of knowledge of the epidemic caused panic and stigma among local people, while low education level and poor health literacy discouraged prevention and treatment of common diseases.

The aim of the MCH project is to improve the access to and quality of health information and services among vulnerable children and women to reduce child mortality, improve women's health and prevent the spread of HIV and other infectious diseases in addition to increase the participation of local people in IEC activities for a supportive community environment.

Project description:

Need assessment and planning,
Renovation of village clinics,
Training of community medical staff,
Community based essential health services to children and mothers,
Health education and promotion of healthy lifestyle,
Sharing of evaluation results and project experience, and
Identification of scale up potential

Project cycle: January 2005-June 2006

Funds: 3.59 million RMB, by the Kadoorie Charitable Foundation

2. Outcome

In 2003, Save the Children worked with Funan County Women's Federation to renovate the clinics and schools of four villages. In 2005, it started to provide community based care for children affected by AIDS, a four-year project that set up 3 children's centres, 1 income generation project and 1 family care project. In 2008, another project providing high-quality health services to vulnerable children and mothers was in place.

In the baseline period, several poor villages were suggested by local partners, where a lot of young and middle aged people migrated out for jobs, leaving children, women and the aging ones at home. Taozhai Village had some households affected by AIDS and had not been covered by the New Rural Cooperative Medical Scheme (RCMS) in 2008, nor the China CARES interventions, such as building a road and a clinic in the village. Finally Taozhai was chosen as the village to implement the MCH project.

Activities:

- Baseline studies (surveys among 200 villagers-80 children, 70 mothers and 50 men), interviews with village doctors and leaders and information collection to evidence project planning with partners.
- Focal point team set up at county level (deputy county governor and focal points from County Government Office, health, MCH and education departments, working committee for children and women and from township level).
- Consultation and management teams set up with regular meetings to encourage different parties to participate.
- Two training sessions among 37 village doctors and women leaders on maternal and neonatal health care, including introduction on common maternal and neonatal diseases and their causes. The participatory training improved the awareness and understanding of MCH services among village doctors and facilitated experience sharing.
- A big IEC event themed TB prevention on World Tuberculosis Day by Funan County Health Bureau, County Women's Federation and Save the Children, attracting an audience of over 300, Funan County TV and Fyang Daily both covered the event.
- TOT among 40 middle school teachers on puberty mental and physical health with discussions on how to deal with puberty problems.
- Training of 42 children on child health and protection with discussions from the children's perspective on the benefits of good hygiene habits and contributions they can make to their communities.
- Construction of a 120 square meter village clinic that meets the hygienic standards issued by the RCMS with basic medical equipment and drugs, clean drinking water equipment and sanitary latrines. The clinic will provide annual

physicals to children under 18 and can also premises for health education. It facilitates the RCMS's process of reaching the village, improves medical infrastructures and ensures the access to MCH services including disease screening.

- Peer education training among 40 primary and middle school students on puberty health and AIDS knowledge. The training turned out effective as the trainees spread the knowledge to their class mates, friends, families and neighbours.
- Physical check-ups for all under three children, growth profiles for each child and growth monitoring.
- Training on breastfeeding among 40 people (pregnant and lactating women, village leaders and doctors) during the International Breastfeeding Week. The training broke the myth that makes mothers favour formula feeding and improved women's knowledge on childhood nutrition. The change of mothers' practices directly benefits the children.
- Training on the *Convention on the Right of the Child* among 40 primary school students. For the first time the students were introduced to the Convention, learning about the rights they are entitled to and how to protect their rights.
- The second township level training of 33 village doctors and 3 village managers on Integrated Management of Childhood Illness (IMCI). Doctor Li from the paediatric department of Funan County Chinese Medicine Hospital introduced 5 types of common childhood diseases and their causes and treatment. The training improved the knowledge of the village doctors and consequently the service quality.
- Establishment of the village clinic that increased the accessibility of health services. The clinic supported by the County Health Bureau building on the RCMS provides health care services to local children and pregnant women.

3. Sustainability

The project under the tremendous support by Funan County Government Office consolidated the partnership between Save the Children and Funan County Women's Federation and also that between the County Health Bureau and subordinate County MCH hospital. It also developed partnership between Save the Children and County Education Bureau.

County MCH hospital provided technical support including staff training, physicals for children and breast feeding and childhood nutrition training. The County Health Bureau provided practitioner training among village doctors while the Women's Federation organized a variety of activities among target populations. To ensure sustainability, the working committee of the project had regular meetings to identify constraints and solutions and to modify the next step plans accordingly.

All parties involved will continue to work for sustainability after the handover of the project to the government. As the head of County Health Bureau said, “we will try to raise more funds to continue the project and at least ensure the well-functioning of the village clinic if we fail to get the next round funds”.

4. Costing

Funds were solely used for project activities, staff and operational cost excluded. This had some impact on project sustainability. Some of the project activities, especially operational costs were covered by the budget of other projects. A lot of human and material resources (activity coordinators and premises etc.) were contributed by partners and communities,

All partners had been actively involved and pledged to provide supporting funds. The Taozhai village clinic will be included into the management of 60 RCMS demonstration sites of the Funan County.

5. Impact

All the participants benefited from the project. As the mid-term evaluation showed, children learned about the project through the training that changed their bad habits and spread the knowledge forward. Pregnant women were also found more aware of ANC, child feeding and child care with greater willingness to learn. The project was well received by local people and all the focal points were dedicated. The training improved the technical competency of community doctors and consequently the quality of services they provided. The project also facilitated the work of the government and raised their prestige among villagers, students and teachers.

6. Innovativeness

- Encourages community participation to increase the sense of ownership. Village level project management team was set up for top down management and accountability to boost villagers’ participation and their sense of ownership.
- Encourages children’s participation and promotes the best interests of the child. A consultant team was set up to give suggestions from children’s perspective.
- Carries out community-based peer education to raise the awareness of self-protection among members and peer education among villagers, women and children to spread the knowledge and increase sense of ownership.
- Creates a community based model for child protection to meet the multifaceted needs of the children. A children’s centre was built, providing each of the 150 children in the center one egg everyday, a measure that raised publicity while providing nutritional support, high-quality health services and safe and interesting place for the children.

7. Lessons Learned and Recommendations

Solid partnership is the key to successful project implementation in addition to staff teamwork and the attitudes of local government directly affect the outcome.

Lack of staff with public health background, which are able to carry out training independently. Most of the training had to be fitted into the timetables of the partners.

It was hoped by local hospitals that the project can be extended to water, latrine and pigsty improvement for the better local sanitary conditions. And partners also expressed their wish to have study tours to other project sites to draw on their experience.

To ensure project sustainability, a number of villagers will be selected as volunteers to deliver disease prevention information to households after training on basic medical and health care knowledge and communication skills. This will enable volunteers to become practitioners in community based maternal and child health care services, which is the fundamental goal of the project.

TREATMENT AND CARE

CONVENTION ON THE RIGHT OF THE CHILD

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
 - a) To diminish infant and child mortality;
 - b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
 - c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
 - d) To ensure appropriate pre-natal and post-natal health care for mothers;
 - e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
 - f) To develop preventive health care, guidance for parents and family planning education and services.

PROVIDE AND PROMOTE HIGH QUALITY TREATMENT AND CARE FOR CHINESE CHILDREN LIVING WITH HIV/AIDS AND HELP PREVENT MOTHER TO CHILD TRANSMISSION

Clinton Foundation

1. Programme General Information

Programs concentrate primarily on the following regions:

National:	Support drug donations and provide technical support to NCAIDS/T&C
Anhui/Henan:	Mature paediatrics epidemic, with most infections occurring through MTCT in connection with tainted plasma selling/transfusions. In Anhui, the economy is primarily based on agriculture, with GDP per capita amongst the lowest in the country.
Guangxi:	Young paediatrics epidemic primarily stemming from MTCT in connection with IDU and sexual transmission. Guangxi is both a source of and destination for migrant workers, and possesses a highly developed transportation network, which facilitates the intra- and inter-provincial flow of goods and people. Its ethnic makeup is also diverse, with around 36% of the population comprised of ethnic minorities.
Xinjiang:	Young paediatrics epidemic primarily stemming from MTCT in connection with IDU. The vast majority of patients belong to ethnic minorities, whose cultural practices make needle sharing common. Conservative cultural and religious beliefs in combination with distrust of Han (ethnic majority) clinicians create significant barriers to reaching infected children.
Yunnan:	Young paediatrics epidemic primarily stemming from MTCT in connection with IDU and sexual transmission. This year, infection by sexual transmission became the most common transmission route for new infections in Yunnan. Economically disadvantaged persons are disproportionately affected by HIV/AIDS; in Yunnan, this is compounded by transportation challenges that often prevent patients from travelling to larger cities for care and treatment. Minority populations also harbour distrust of modern medical practices, as they are often introduced and administered by the government and the Han ethnic majority.

This program provides:

- Strategic support for program design and recommended methodology
- Technical support for treatment guidelines
- Financial support to:
 - i. Program coordinator for management at the local level
 - ii. Doctors for subsidy on patients following up

-
- iii. Patients for opportunistic infections, lab tests, transportation, nutrition, etc.
 - Clinical training and mentoring in aspects of pediatric HIV treatment
 - Donations of all pediatric ARVs and other therapeutics (SMZ)
 - Direct program support on site to four provinces

2. Specific Projects contents:

In 2008, CHAI helped to initiate over 300 new children on ART. This has been accomplished using a two-pronged approach, namely the provision of technical assistance to NCAIDS in the national scale up of paediatric treatment and diagnosis, and the provision of direct support to the provincial CDC of four provinces (Anhui, Xinjiang, Yunnan and Guangxi) to enhance the quality of paediatric HIV/AIDS care.

● Treatment and Care:

Overall Treatment and Care Goals:

To increase the numbers of paediatric HIV/AIDS patients on treatment, as well as to monitor their status and ensure that they receive quality care.

- a) Provided direct consultations for pediatric patients, using an international pediatric HIV/AIDS expert in conjunction with local CF pediatric specialists.
- b) Provided clinical mentoring in aspects of pediatric HIV treatment through international consultations. In Yunnan and Xinjiang, CF clinicians located in our Urumqi and Kunming offices provide ongoing support for local doctors.
- c) Provided financial support to sites in Guangxi, Yunnan and Xinjiang.

Partner:

National partner: NCAIDS

- Anhui partners: Anhui BOH, Anhui CDC
Primary focus in: Improvement of clinical and management systems and the integration of patient follow-up into the Government's routine activities.
- Guangxi partners: Provincial CDC, Red Ribbon Centers
Primary focus in 2008: Help to enrol new patients and improve patient management, particularly opportunistic infection (OI) management.
- Yunnan partners: Yunnan BOH, Yunnan CDC, Red Ribbon Centers, ACC
Primary focus in 2008: Improvement of case finding methodologies, referral systems and clinical skills.
- Xinjiang partners: Xinjiang BOH, Xinjiang CDC
Primary focus in 2008: Scale up basic training in new sites and encourage case finding.

Programme Results:

300+ new children on treatment, with the majority of identified patients stabilized in Yunnan, Guangxi, Xinjiang and Anhui.

● Case Finding Trainings:

Goal:

Improve the rate at which children are identified, with particular emphasis on identification at younger ages.

- a) Held case-finding trainings in Baoshan and Lincang Yunnan (projected to continue through 2009, with five to seven more trainings planned).
- b) Locations were selected due to low pediatric numbers in comparison to relatively higher numbers of adult patients, suggesting an inability to accurately identify HIV/AIDS pediatric patients.
- c) Target groups were pediatricians, MCH doctors, internal medicine doctors, and others who are likely to first encounter a sick child before they have been identified as HIV+.

Results: Pending, as only begun in late fall.

● **EID/EIT Training:**

Goal:

In concert with case finding trainings and PMTCT, both the EID/EIT lab support and the trainings were aimed at identifying infected children as early as possible to improve the chance of survival and the quality of life.

- a) Collaborated with MCH and NCAIDS to support a large-scale EID pilot program.
- b) Laboratory capacity-building to perform DNA PCR testing completed in six high-prevalence provinces and the trainings for DBS specimen collection at the rural community level is scheduled to begin in the last quarter, with the goal of rolling out services by early 2009.
- c) CHAI implemented an EID program directly through its Yunnan treatment cooperation, starting in five key counties in October 2008. China needs this crucial new initiative to reach the vulnerable infant population. It is a key link to PMTCT, as EID is expected to substantially reduce sickness, disability and the early death of infants with HIV by linking diagnosis to immediate ART treatment and care in the early months of life.

Results: Ongoing as majority of implementation activity occurred in the fall.

● **Grassroots NPO Capacity Building and Program Support:**

Goals:

- a) To improve organizations' capacities to better create and implement PLWHA programs by involving technical experts, international experts, as well as grassroots organizations from throughout the country during the discussion of individual programs' frameworks.
- b) To provide financial and technical support for local-led project proposals with preference given to those incorporating pediatric support.
- c) Co-organized a capacity building workshop for over 60 grassroots HIV/AIDS organizations.
- d) Provided funding to the top seven small organization proposals focusing on improving treatment and care of PLWHA particularly those focused on pediatric needs.

Result:

According to participant feedback – both verbal and through an evaluation form – significant gains were made by the participants in understanding how projects are commonly structured and what constitutes a successful project proposal.

● **Procurement and Forecasting Support:**

Goal:

To improve drug access system so that drugs are accurately forecasted, acquired and distributed.

- a) Facilitated the donation of all pediatric ARVs and SMZ
- b) Aided the Division of Treatment and Care to improve accuracy for 2008/09 forecasting of pediatric formulation
- c) Created data management tool to quickly and accurately process national pediatrics data, which can then be used for analysis and forecasting
- d) Created a long-term drug forecast for China's pediatric drug needs and costs through 2015 with input from foreign experts and NCAIDS

Result:

Successfully completed all 2008 donations and improved forecasting methodology thereby preventing further drug shortages at the national level.

3. Programme Sustainability

All of our programs are designed with the intention of increasing the country's human resource capacity to treat HIV/AIDS patients. Our treatment support is aimed at improving the knowledge and skills of local doctors in order to improve overall care of HIV/AIDS paediatric patients. Trainings augment direct interactions, and are often used to target those medical and social support personnel who otherwise have limited exposure and knowledge of HIV/AIDS treatment as it pertains to children. Cooperation with national authorities serves to improve the overall care and treatment system, with lasting results, such as improved treatment guidelines, better drug supply systems, more accurate procurement and forecasting procedures etc.

4. Cost Effectiveness

The CF China supported paediatric program has committed funds that ensure that our programs can continue in conjunction with our national partners.

5. Conclusion

This program is ongoing in each of the various activity areas. The Clinton Foundation's goal is to work closely with our government partners and help them to achieve their goals. We have found this strategy to be highly successful.

樊林/Emily Weaver

Clinton Foundation

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COMMUNITY BASED CARE FOR MOTHERS AND CHILDREN AFFECTED BY HIV/AIDS

UNICEF (China)

Focus area: Care and Support

Year: 2009

Contact: Ms Hong Fei, HIV/AIDS Section, 86-10-6532 3131

Summary:

In order for each infected person to live a longer, healthier family life and to ensure their children's learning and health, in 2003, the Chinese Government promulgated the "Four Frees and One Care" policy. For quite some time, majority of the HIV positive women and children and the children of the infected parents have not yet received effective care and treatments. This is due to many factors, including insufficient services as a result of scarce capacity of the local finance and personnel,, as well as the many issues faced by majority of the PLWHA, such as economic factors, psychological stress, social and family discrimination, personal knowledge, skill levels and so on. In order to better explore the approaches to effectively implement the "Four Frees and One Care" policy, UNICEF in China is cooperating closely with the Chinese Government and have carried out pilot programs in Henan, Yunnan, Guangxi, Sichuan, Xinjiang and Shanxi provinces. The 6 pilot projects aimed at providing door-to door regular services, community based social workers and establishing better facilities. This was achieved by utilizing the program funding to support Government institutions, so to effectively extend the existing service from service-center based format into family and community-based services. Moreover, the pilot projects also intended to enhance the initiatives and capabilities of the infected women and children in using and improving the services. This in turn was fulfilled by making use of project funding and technical support to set up HIV-positive women/children self-support groups.

Good Practice:

The relevant cases mentioned here described the experiences of the 'Chinese government - UNICEF joint project' gained in 2006 - 2008 from the pilot programme in several provinces. To summarize, these experiences include several aspects related to China-UNICEF AIDS prevention projects'. Firstly, the project supported the grass-roots volunteers from the counties to participate in family cares in their communities, as well as the challenges faced by the measures of effective AIDS interventions. Secondly, the cases also summarized the outcome of the projects over the past two years. The overall project was carried out on the basis of two aspects 'Community based care and support for HIV positive women and children' and 'community based care and support for HIV/AIDS-affected children and their family'.

The project tries to support and build up a capacity and system with community level service, mechanisms for family and community care, as well as a mechanism to provide community-based care for children affected by HIV/AIDS, aimed to achieve the goals as following: 1) to increase women's utilization of VCT services and PMTCT services. 2) Increase

the utilization rate of condoms to prevent family transmission; 3) improving adherence through providing treatment and care service for HIV positive children and adults; 4) enhance the capacities of HIV positive women, children, their family and the community to better respond to HIV. 5) Provide care and support for children and families affected by HIV by conducting income generation activities in order to enhance the quality of their life.

The project emphasizes and encourages the participation of the beneficiary, so to reduce stigma and discrimination. One of the most important strategies is to regularly organize community members and beneficiary to carry out group discussions and in-depth interviews, so to provide rich and detailed information of the community, which is very helpful to the implementation of the project. This high-quality qualitative information is proved to be much more valuable than the data collected at baseline, which can help the project understand the real need of the community and adjust the responses to fulfill the community's needs, as well as provide evidence for policy development. A number of central and local government policies were also developed based on those practices, which has also ensured the sustainability of this project. The project has strategically developed a variety of practical guidelines and manuals, as well as supported the response capability of the local services providers and community members through different kinds of trainings.

Over the past two years, the programme services covered over 5000 women and 700 children living with AIDS; and 9,200 children affected by HIV/AIDS. More than 70% of the women and children were involved in the psycho-social support training, group activities, peer support and family activities such as regular follow-up. 90% of AIDS-affected children and their caregivers received support. The correct information also covered 90% of the community members, not only reached preliminary targets of the project, it also secured the long term development of the project and pave the way for a solid foundation.

Potential application:

Applicable to poor-resource grass-roots level, including: weak capacity of service providers & system, lack of funds, and relatively severe AIDS epidemic areas.

Issue and Background:

- Till September 2005, 1535 reported HIV cases were children; Roll-out of paediatric care started in June 2005. Paediatric AIDS drugs are not yet readily available in China. [often liquid form so children can ingest them]
- At the end of 2004, Prevention of Mother-to-Child Transmission projects were carried out in 5 provinces and 8 pilot areas, with counselling services and HIV testing for 310,000 pregnant women at ante-natal clinics. 392 women were tested HIV positive [0.12%]. Mid-Term Review of Mid Long Term HIV Prevention and Control (1998-2010); 76% of women in the China CARES pilot locations have received PMTCT services.
- Medical systems for mother and child were separated.
- Very limited cotrimoxazole use for pediatric HIV/AIDS patients.

Based on what have been mentioned above, in 2006, in line with the development of the Chinese Government to achieve its objectives, UNICEF AIDS project (2006-2010) prioritized the needs of "positive mothers & children and their families in community care", which focused on the care and support for women and children. The plan of the project aimed at establishing a model which can fulfill the local needs, through supporting the building-up of local structures, policy development,

technical guideline development and all beneficiaries. Meanwhile, the project plan also supported the in capacity-building of the project participants and community participants. To contribute to children and adolescent related results of the 2006-2010 National HIV/AIDS Action Plan with respect to the goals of MDGs and HIV/AIDS UNGASS goals.

Project Goals:

Support the development of national level guidelines, strategies and best practice collection for family/community based care for mothers and children in demonstration of national scale-up.

Expectation of Project Outcome :

90% of HIV-positive mothers and children have access to care and support services by 2010 in 6 Provincial project areas.

Project Principle:

1. Scientific knowledge acquisition and dissemination on children, young people and AIDS to inform programmatic and policy decision-makers
2. Advocacy to leaders, policy makers, programmers, donors, the general public and children themselves to increase understanding of HIV/AIDS, its impact and actions to be taken.
3. Demonstration and implementation of good practice for national scale-up by Chinese Government in partnership with international and Chinese civil society
4. Partnerships for, and with, children and young people—leveraging action and resources

Strategy – Based on the Effect of the Project

1. Collaborating with WHO, UNAIDS and UNTG, so to produce materials which could demonstrate a) the implementation and scale-up of national policies ; b) family and community HIV/AIDS care, which is provided locally ; c) the support to behaviour changes
2. Guidelines and policy development on family and community education on HIV/AIDS; demonstration through professional trainings in support of national scale-up in collaboration with WHO, UNAIDS and UNTG
3. Guidelines and demonstration of the participation of the PLWHAs and young people in the development of income-generation [livelihood skills] and support from the intervention of family/community4. Promotion through the "Global Campaign" to implement national policies at local level for children living with HIV/AIDS and pregnant women through awards, best practice collection and advocacy events.
4. Increasing the awareness and knowledge of the rural health care providers regarding to the information of ECD HIV/AIDS and HIV/AIDS itself. The health care providers are in general involved in projects related to PMTCT, MCH and paediatric HIV/AIDS care.

The model is consist of 5 components:

1. Capacity and system building for local service providers
2. The establishment of family and community-based care mechanisms;
3. To establish community-support mechanisms for women to maintain health, Medication and prevention of further spread;
 - Set up self-support groups
 - Income generation activities – for women and children to provide financial support for families
4. The establishment of community-based care and support mechanism for children affected by HIV.

-
- Providing home –based care for children
 - Support school-age children to go to school and provide vocational-skills training for older children and create working opportunities for them.
 - Provide psycho-social support and peer support for children.

5. The development of prevention materials to fit into local culture, community mobilization - to reduce social discrimination.

The five components described in this model are prioritized differently based on the specific circumstances of the project area. Meanwhile, different focuses are given according to different needs.

1) Capacity and system building for local health service provider

Local health authority and its staff is the key source, who can provide care and support for local women and children infected and affected by AIDS. It is the key to ensure the sustainability of the projects; therefore the project has paid special attention to support the system building, job creation and the ability of the staff. The newly recruited community social workers can provide door-to-door follow up services as the provision of case-management style. At the same time of the establishment of the appropriate mechanisms, training workshops and seminars are also provided to local project managers and other project staff to support them to build up the techniques on project management. The project also supported in improving the equipment for the project area, which can be formed starting from the needs of women and children, family and community service networks and mechanisms.

2) the establishment of family and community-based care mechanisms –Family & community support services mechanisms is led by local AIDS coordination office, a key department in charge of the case follow-up, multi-sectoral participation in problem-solving; through a combination of local conditions, local Woman's Federation, CDC and CNCCC working closely to detect the needs of women and children. Many activities fulfil the needs identified, such as cash transfer, income generation activities, emotional comfort, psychological support, support to reduce social discrimination, medical and health support, school support and education, rights of women and children to maintain the support of and addressing other specific issues.

3) The establishment of the support system for women to maintain health, medication and prevention of further spread - Community service network and PLWHA self-support groups through counseling, group seminars, training and other forms, to increase the capacity of women in use of VCT services and increase VCT services utilization, at the same time providing basic hygiene education, skills for looking after children, HIV prevention information and information about local health service availability to women living with HIV. Meanwhile providing adherence counseling and regular follow-up services to positive women and children who are currently on treatment through the self-support groups and service network.

- Set up self-support group

In order to ensure the sustainable development of the project, the project supported those infected women set up "positive women self-support group", "income generation self-help association" and other forms of self-help groups to help strengthen the capacity of women themselves, at the same time also established a mechanism for grass-roots women's

participation and community service network. Within the two years, a total of six project areas to assist 37 PLWHA self-support groups, which can provide care and support service to more than 2700 HIV positive women and 600 positive children. At present, each group can provide a certain degree of peer counseling, home visits and door-to-door services such as medication supervision.

- Income generation activities – for women and children to provide financial support for families

Most AIDS patients have lost the ability to work during the period in the incidence, more often, they can only wait for the Government to maintain the relief of their families' livelihoods. In order to alleviate the difficulties of families living with HIV/ AIDS and improve adult patients and children's nutritional status, the model intended to use income generation activities as one of the ways to improve the financial status of families affected by AIDS, through providing cash transfer and technical support to positive women or families affected by HIV/AIDS, to enhance their self-development and self-awareness and abilities to rescue themselves out of the poverty, at the same time to build up positive living attitude. In the project area, community members took part in the discussion of the ways to conduct income generation activities and so on, select a different production methods, such as the provision of small start-up capital, or to provide free production of goods and production materials, technical skills to support farming, etc... meanwhile support the families to re-think women's role in the family, and encourage positive women as the main target of production. The production of various forms of local self-help activities to improve the mental outlook of people with AIDS, and enhance their confidence in life.

4) Establishing community-based care and support mechanism for children affected by AIDS - to ensure children who lost one or both parents due to AIDS, still living in a family environment, and continues living in their community and siblings, the project supported local civil affairs to add additional post of social workers and equipments needed to provide home visits and support services, especially focusing on the promotion of family foster care and other forms of home-based care, to ensure affected children orphaned by AIDS to grow up healthily in the family environment. To support this project at the community level, a wide range of support activities were carried out:

- Provide support to children's families
provide financial support according to local civil affair departments standards for foster families, to ensure their basic living needs. Currently, all children live in the foster care families have received financial assistance in all project sites. The experiences gained over the past two years come to the conclusion that in addition to orphans and vulnerable children to provide all kinds of help and support, their caregivers and guardians are also in need of technical, psychological and financial support and help. At present, the project point of caregivers and guardians have received a number of the corresponding trainings.
- Ensure schooling for school-aged children and vocational training for older children and create opportunities for jobs
At latter period of the project, cash transfer mainly provided by the government and other non-governmental partners. Therefore the project has re-focused to reduce discrimination in

school, in order to ensure the continued development of the project. At the same time, older children began to be provided with vocational skills training and entrepreneurial support. By 2008, more than 500 children received vocational training, of which 90 percent after the age of 16 applied the skills they have learned and found a job. The content of support for older children, vocational training and entrepreneurship has entered the provincial and national policies. Relevant guidelines and training manuals to provide guidance to the mobilization of enterprise support to older children affected by AIDS are in the stage of drafting.

- Forming children's in peer support and provide psychological support to children
Projects through community volunteers, PLWHA self-support groups conducted a variety of entertainment activities and support children to foam in peers, and through the fun activities to build up friendship and increase communications which has effectively reduced discrimination and stigma. Over the past two years more than 300 children have been foamed in peer support and 2700 children participated in the regular group activities.

5) The development of prevention materials to fit into local culture, community mobilization - to reduce social discrimination - discrimination against women and children is one of the greatest obstacles that have hindered the use of social services. In order to create a favorable environment for the community care project, and to go along with the national public awareness campaign, the community volunteers go to schools, families and public places to carry out various forms of publicity and educational activities, which covered more than one million people in the project area. Over the past two years, the project has developed a variety of prevention materials which could fit into local cultures including manuals to support the midea, grass-root NGOs, women and children.

Progress and Results:

Within the two years, over 70% HIV+ women covered by the projects have accessed information on health care, care taking, and positive prevention and services availabilities. Reported by the mid-term review, the knowledge of positive women on HIV related services have greatly improved compare with the baseline data. In addition, women's groups and service network providing drug adherence counselling and monitoring support raising adherence levels from 60% to 90% among women participating in the programme.

The income generation activities have also been provided as an effective model which could support PLWHA. According to the mid-term review result, since the project started in 2003, in some project area, families which have involved in the income generation activities has shown significant increased income levels. From 2006 to 2008, in some project county, the per capita annual income of affected families increased by 38.08% (control group, by 20.16%), and the gap between affected and unaffected families was lessened. In project sites where cash subsidies were stopped and income generation programmes were implemented, it was demonstrated: 1) per capita income of beneficiary families was increased; 2) sustainable models of "household support" models were established; and 3) the underlying vulnerability of the families affected by AIDS to poverty can be addressed. These income generation programmes is an example of an interventions that can be scaled-up.

In the area of providing care and support to children affected by AIDS, the projects have also

achieved great impacts. Over the past two years, project sites have covered 90% of children affected by AIDS that was living in extended or foster families, have attended schools and have received living assistances. Caregivers also received skills training to look after children. The MTR result shown: vocational trainings were also provided to over 500 children and 90% of them were employed after they turned 16 years old.

To reduce discrimination and stigma, the project mainly focused at two aspects, which are prevention knowledge and behaviour changes. 2006 baseline result shown: due to 03-05 period project were focused only on children affected by AIDS, the affected families had much higher awareness than the control groups, in 2008, the awareness among the affected families remained at the same level while that among the control group became higher. This shows the AIDS information is being communicated to the whole community beyond families affected by AIDS. In addition, the number of reported children affected by AIDS has increased. In 2003, when the project was started, only few children accepted the assistance as receiving assistance meant revealing their parents' HIV status. In 2008 however, the number of children who sought help was 10 times higher. This shows the project has reduced stigma and enabled more children to seek care and support without concerns about stigma.

Project sustainability- When “sustainability” is discussed in the context of development, it connotes a degree of ownership, a “buy in” by the governing agents or those holding authority in a community. Moreover, if a project can fulfil the needs of one generation, as well as provide skills for next generation to meet their own needs, and it is also considered as the implementing body's including local NGO, PLWHA and other members within the community, and the participation of community children and youth, support them to build up a network, and the skills of those parties is strengthened. If the answer is positive, then we can say it is a sustainable project.

In this project, local government through various channels provide family and community services, 90% local implementers has acquired project management skills through workshops and trainings. A service framework involving women and children living with HIV/AIDS, children affected, grass root service providers, and social workers has been set up. This framework has been included in local government working plans.

To build up project ownerships to the community members, the participation of community members and the target population is crucial. Project has widely mobilized PLWHA, especially positive woman, children affected by AIDS and their family members, youth, adult, as well as school teachers and community leaders. Within the two years, in the course of the project point of a region involved in a considerable number of the fixed pattern. The successful experiences of setting up of women self-support group and income generation activities have proved that family and community based care for women living with HIV/AIDS improved the economic situations of the affected families, reduced the discrepancy between affected and unaffected families, boosted women's confidence and self reliance, and above all, addressed the root causes of poverty of the families instead of providing subsidies only. In project sites where cash subsidies were stopped and income generation programmes were implemented, it was demonstrated: 1) per capita income of beneficiary families increased; 2) sustainable models of “household support” models were established; and 3) the underlying vulnerability of families affected by AIDS to poverty can be addressed. These changes has proved that even the project ends at 2010, the skills gained by

positive women during the project period can help them to some extent to change their living environment.

Another effective method to improve the sustainability of the project is to develop as far as possible, a variety of support or guidelines, manuals and promotional materials for behavioural change. In two years time, based on the practical experience, a wide range of support and promotional materials were developed for the project continuation and to promote and expand the coverage.

Challenges and Next steps:

- **Establish and improve national monitoring system for all vulnerable children, especially children affected by AIDS. Based on the information and data provided by the monitoring system, set up national protection provision of institutional mechanisms, including adequate funding** - the MTR found that the original cash transfer of 100 Yuan/per month for support school-aged children's daily life, education and health were shifted from the project to local civil affairs departments. Due to government with lack of funding to continue this support, this resulted in a big decline in school attendance rate among older children, thus demonstrates the assistance system financed by the programme is not sustainable. It is recommended an advocacy strategy for ensuring children's attendance is drafted and older children vocational training is instated for those who choose not to attend school.
- A variety of mechanisms for community level support and services have been established, however the quality of support and services have to be improved. Particularly psychological support for positive women and children affected by AIDS, currently local service provider's ability and skills to provide care and support is still weak, and needs to give more attention.
- At present, all social workers involved in the project is prepared outside the country system, and the wages and labor expenses are paid by the project. So after the end of the project, social workers need to continue to participate in the takeover of the government and financial support to ensure the project sustainable development. In some areas, the ability of the social workers needs to be improved, and discrimination still exists in some social workers, which is conducive to the project activities.

PREVENTION

ENCOURAGE CHILDREN AND YOUTH PARTICIPATION-REDUCE VUNERALBILITY AND STIGMA

1. Provide comprehensive and internationally recognized knowledge on AIDS prevention to all, especially to adolescents.
 2. Facilitate the participation of children and adolescents in prevention, so to meet their real needs with an innovative approach to community-based care that aims at:
 - (a) Active learning by children on the knowledge of AIDS, including prevention information;
 - (b) Effective communication with peers to spread prevention information and reduce risky behaviors;
 - (c) Reduce sigma for children and families affected by AIDS.
- Under the Same Sun- International Policy Consultation for the Care and Placement of Children Affected by HIV/AIDS in China, Zhengzhou, Henan Province

MSIC MIDDLE SCHOOL AIDS PREVENTION AND REPRODUCTIVE HEALTH EDUCATION

Marie Stopes International China (MSIC)

Background

Earlier age of sexual maturity and later age of marriage prolong the interval between the two, while adolescent reproductive health education has yet to meet the needs of this age group. Most of the rural youth aged around 16 seek jobs after graduating from junior middle school, a large number of whom becoming migrant workers in cities. Away from the care and education by families and schools, these young people have little access to reproductive health information. Will they be able to protect themselves against risks in this ever changing world full of temptations?

There is a pressing need to meet this challenge. Apart from existing interventions, the key to address the root of vulnerability of youth is to equip them with sufficient risk prevention knowledge and skills before they experience what the society is like. In this way young people are able to make the right decisions when facing problems.

Objective

Raise the awareness of middle school students of reproductive health and STI/AIDS prevention with a right attitude toward sex and improve their mental and social adaptability.

- Raise the awareness of reproductive health and AIDS education among local education sectors and build capacity for local teachers.
- Standardize the implementation of the *Guidelines on AIDS Prevention Education in Middle schools* among project schools and integrate AIDS Education into routine curricula.

Project Description

1. Identification of Stakeholders

Different stakeholders involved in middle school project:

Stakeholders	Significance	Specificity
Direct stakeholders	Education sector	
	School leaders	
	Teachers	
	Students	

Indirect stakeholders	Parents		
	Health sector		

2. Need assessment

A survey for a comprehensive need assessment is necessary to better understand all the stakeholders and more importantly, to know the gap between goals and realities and the approaches needed to meet the goals.

Survey examples:

Purpose:

Know the situation of reproductive health education in local schools;
Identify the constraints in implementing the Guidelines

Methodology

Quantitative and qualitative

Outline

Education sector	➤ Attitudes toward AIDS and AIDS education; ➤ AIDS awareness
Health sector	➤ Channels to know AIDS knowledge; ➤ AIDS and reproductive health education in the schools
School leaders	➤ Understanding and implementation of the Guidelines ➤ Suggestions on the project;
Teachers	➤ Opinions on middle school AIDS education;
Parents	➤ School managers' attitudes towards AIDS and reproductive health education;
Students	➤ Attitudes among teachers and students towards AIDS and reproductive health education; ➤ AIDS education in schools ➤ Opinions IEC materials and activities.
Note: Topics were chosen according to different target populations	

Results of the survey were analysed as evidence for partner identification and detailed activity planning.

3. Launch meeting

Participants

- Education and health officials at all levels
- School managers and teacher focal points
- Experts
- Personnel with project experience from education sector.

Aim

-
- Introduction of the background, significance and methods of the project
 - Trust building with counterparts
 - Sharing of need assessment results
 - Identification of project sites, managers and plans.
-

Action plan

Name	Time	Participants
Primary TOT	Within one month after the launch meeting	30 teachers from project schools
demonstration Class	After the TOT	30 teachers and 20-30 students from project schools
TOT at county level	Within one month after primary TOT	Teachers from project schools
Advanced TOT	Mid term	30 excellent teachers
Development and distribution of IEC materials	Quarterly	Project staff
Student activities	After	Students and teachers
Monitoring	After TOT	Project staff and stakeholders
Experience sharing meeting	Within one month before the end of the project	Excellent teachers, school managers, government officials, experts and potential partners.

Ministry of Education launched the *Guidelines on AIDS Prevention Education in Middle schools* in March, 2003 to include AIDS education into primary and middle school curricula. AIDS education are mainly for students from Grade 7 to 11, two sessions each school year, 6 sessions in junior schools and 4 in high schools in total.

The two-year MSI China project in Zhoukou, Henan Province from 2004 to 2006 was remarkable with the support by Zhoukou City Education Bureau.

A 13 year old girl got pregnant, but her parents thought she was just having stomach mishaps or getting on weight. At last the girl gave birth to a baby. This would not happen if parents hadn't been that ignorant.

---Qi, A middle school teacher



A survey among students in a middle school showed that only a few teachers had taught about AIDS knowledge, saying that there was no need to worry about mosquito bites.

4. Project activities

4.1 TOT

Style

Participatory

Contents:

Sex education, values, and AIDS prevention education and life skills training.

Objectives:

- Know the difference adolescent sex education makes.
- Learn to use participatory methods;
- Acquire the skills for adolescent sex education and life skills training
- Learn about AIDS and drugs.

4.2 Demonstration class

Style

Participatory

Contents:

Puberty health, life skills and AIDS knowledge

Objectives:

- Demonstration of participatory learning.
- Acquisition of puberty health knowledge and life skills.

4.3 School activities

Forms:

Zoom in: photos to document the situation of reproductive health in middle school students

Objective:

improve students' understanding of reproductive health

Participants:

Middle school students

Activities

Students received training and took photos that reflected the way they look at reproductive health. A documentation was produced after discussions on the photos.

Supplementary activities

- Teaching in class
- Focus discussion
- Writing contest
- Blackboard newspaper contest
- Peer education training
- Letters to parents/ friends
- Speech contest



Participatory methods refer to the practices that use games, discussions, etc. to encourage all the participants to get meaningfully involved in an activity.

Drugs are a big problem in Guangxi, my home town. A lot of young people use drugs and face a high risk of HIV infection. Some of them have just finished school education. That's why there are so many communication billboards here against drug using. We need to learn to protect ourselves against drugs.

Chen Zujin, a middle school student from Guangxi Province

4.4 IEC materials

TOT manual

You and Me pro bono newspapers:

Quarterly distributed,

Free and feedback welcomed, and

Modification according to the feedback.

Newsletters distributed together with the newspapers for teachers to know the progress of the project and to update their knowledge and skills.

End of project meeting

Time:

Within one month before the project ends.

Objectives:

Collect experience and lessons

Project promotion among other areas and potential partners.

MSI China

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MSIC UNIVERSITY PEER EDUCATION PROJECT

Objective

Develop volunteers who have been trained on reproductive health and AIDS prevention to carry out peer education, spread the knowledge and life skills and promote reproductive health in project universities.

Partnership

Willing university Youth League Committees with agreements signed to develop volunteer team for peer education in university.

Activities

Team building

- Selection of volunteers

Volunteers were developed from the existing student societies or committees or specific peer education student associations/communities were set up. A variety of indicators were used to assess the qualification of applicants, including motives, personalities, language skills and popularity.

Volunteer selection procedure, Guangxi Traditional Chinese Medicine University:

Application opens to juniors and sophomores at the beginning of the session and recommendations by Youth League Committees of all departments were welcome. 50-60 applicants were selected to carry out 2 sessions of peer education and active and dedicated ones were picked out as qualified.

- Training

2-3 sessions of peer education were carried out among the qualified to decide the final ones to be peer educators who later received tailored training by MSIC.

Training scheme				
Phase	Training	Targets	Contents	Days
Beginning	TOT	volunteers	Knowledge on reproductive health and AIDS prevention	2
Second month	Communication skills	Peer educators	Communication skills	1
third month	Knowledge on reproductive health and AIDS	Peer educators	General, specific and updated information on reproductive health and AIDS prevention; life skills	1

	prevention; life skills			
Seventh month	Team and project management basics	Volunteer team managers	Introduction on voluntary services and volunteerism, team management and project application, implementation, management and evaluation	1
ninth month	Training on gender	Peer educators	Basics on gender and homosexual subculture	1

● Team building

Usually 5-10 universities were covered by the MSIC peer education project that develops local volunteer teams usually consisting of university focal points and volunteers. Meetings were held monthly to share progress information and management experience and to plan for activities.



2 hour session

Pre-training survey
 10 min: know each other
 5 min: rule making
 15 min: discussion: values and relationships
 10 min: desensitization to sex
 10 min: contraception and abortion
 10 min: demo-condom use
 45 min: AIDS prevention
 10 min: life skills
 5 min: warp up
 Post training survey

Volunteers:

Zhou Fangli: MSIC gives me the opportunities to do something meaningful.

Li Xue: Sometimes I feel tired as I've spent too much time on peer education, but every time I see the volunteers, I get cheered up.

Sun Xin: I like my fellow volunteers. We are like a big and warm family.

Yu Xiaofeng: My job is about environmental protection and I'm also a volunteer in health promotion. This enriches my life.

Training combined reproductive health and AIDS prevention information delivered in a 2 hour structured peer education session supplemented by other activities.

Outcome

MSIC started sex education project in universities in 2001, its work covering over 60 colleges, training more than 3,500 peer educators, with the participation of over 1000000, playing a specific role in promoting reproductive health among university students.

Sustainability

At the end of the project, the student communities had been able to implement projects independently and raise funds from colleges, hospitals, local CDCs or NGOs.

MSIC values the influence of college Youth League committees whose attitudes largely decide the quality and sustainability of the projects. Peer education has been well received by project colleges, some of which allocated earmarked funds for IEC on reproductive health and AIDS prevention, shifting from operational to financial support, a key to successful project implementation.

Development of Youth Leaders

A group of volunteers dedicated to pro bono activities and promotion of adolescent reproductive health were identified through the project. They are the sources of youth leaders. MSIC believes that the development of youth leaders mobilizes young people, increasing their participation in promoting adolescent reproductive health and facilitates the shaping of civil society. Therefore, MSIC developed a youth leader training mechanism.

A two-front approach combining learning and practices is applied to the training with particular attention to practices. The development of youth leaders has the following steps:

Focus on universities and radiate to middle schools

Part of the youth leaders' job is to communicate with adolescents from different backgrounds to understand their needs in reproductive health and AIDS prevention. Therefore, it is necessary to increase the presence of youth leaders in middle school reproductive health and AIDS prevention projects. Interventions include Q & A through correspondence, participatory training, demonstration classes and monitoring.



Reach out to communities

The volunteers also reach out to out of school youth. Their activities include AIDS prevention training among migrant youth, TV and radio programmes, road shows and IEC activities in factories, etc. .

These activities are mind openers that enable the volunteers to tailor their activities to different types of youths and develop advocacy capacity so that they can contribute more.

Photos: Volunteer activities, MSIC



Training

Three summer camps for excellent volunteers have taken place since 2005, where youth leaders were trained on team management, peer education basics, volunteer development and leadership.

MSIC attaches great importance to the empowerment of youth and uses a two-pronged approach integrating learning and practices to improve the capacity of the volunteers. The training was part of the MSIC university project, but participants were not limited to university volunteers. Attended were also workers, volunteers from other sectors and young NGO staff. Individual capacity building and empowerment of youth among the priorities of MSIC projects encourage young people to shoulder greater responsibilities. Shows, outward bound training, debates and daily management by youth themselves all contributed to the success of the summer camps.

The MSIC youth leader training took place during the third MSIC volunteer summer camp in Xi'an in August, 2008. Participants went through an online selection process. 37 applicants from 11 provinces were selected among 100 to become campers after one month's practices. The campers had discussions on love, inspiration, innovation, perception, speculation and teamwork to learn about leadership. They also interviewed target populations while carrying out training, shows and IEC activities among migrant population.

The three summer camps trained over 100 youth leaders who have been actively advocating attention to adolescent reproductive health and AIDS prevention, devoting themselves to the universal access to information and stigma reduction. Whether their real-life jobs are related to health or not, the youth leaders are contributing to the promotion of youth reproductive health in their own way.

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INTERNATIONAL PRACTICE

MEMORY WORK: A CHILD CENTRED APPROACH TO HIV & AIDS

Health link Worldwide



Nasima loves colours...

Nasima (name changed for confidentiality) is a 13-year-old girl from a rural part of Eastern India. She lives with her mother and her two younger sisters. You may initially find her very quiet, but as you start talking with her you get to know how vibrant and colourful she is. She loves wearing gorgeous sequined sari (embroidery) clothes, especially in her favourite colours such as red, yellow and maroon. New clothes work wonders for her. She is quite fond of watching TV, an influence evident in her special fondness for applying makeup, doing her hair and using costume jewellery. She has a few friends, among whom her cousins are very close to her. She is also an active member of a children's club and in fact takes on lot of responsibilities in its activities.

A year ago Nasima was quite different. But her father's death suddenly changed her and her life. Her father was sick and she heard others saying that he was dying of AIDS, an illness which was not good. Her mother and all the daughters had to go for tests and she heard that her mother and younger sister had the same illness as her father. Some of their relatives helped them initially but soon everyone started avoiding them. Nasima dropped out of class IV and her youngest sibling preferred staying away from the pre-school centre. Their mother kept struggling to sustain her family with a meagre amount of Rs 150 earned as rent from a shop. There were no savings and no support. They lived in constant fear of being displaced from their home.

Nasima could sense that they were now different from others, a difference which was very cruel and harsh. She stopped talking with other people, especially with her mother, who herself was very upset, coping with the entire situation. Both of them mourned the death of Nasima's father but they had no one with whom they could share their grief. Sad memories haunted them and they drifted apart.

Then a health worker started visiting them and talking to them individually. She was a counsellor and talking to her was a huge relief! Nasima's mother saw some hope but not Nasima. The counsellor organised a club with group sessions with parents and children. After much persuasion, Nasima agreed to attend the sessions and soon found many other children like her. Initially, she only spoke to them since the interactive games made her do so, but soon she herself started to enjoy playing with them, drawing pictures, singing songs, dancing and talking.

The same happened with her mother, who now felt more confident about speaking of her life. One day she decided to share her problems with Nasima, who she realised could be her best support. The mother and daughter became closer. Nasima now knew what HIV was and how it spread. She realised that it was not dirty to have the illness and that everyone should have a happy life. Moreover, they soon realised that they had so many good memories to share and if they all remained together, they would be able to help each other. Nasima helped her mother bond more with her two sisters. She took special care of her mother and her youngest sister.

Now Nasima is her mother's best friend and a friend of many others too. The club of which she is a member of is now very popular. It is an open space for all children in

the locality to play, to learn and to have fun together. She helps arrange meetings in the neighbourhood, and encourages adolescents to take an active part in the sessions and the community activities. Everyone actively takes part in all celebrations such as Children's Day and Independence Day, as well as other social programmes. Nasima is now a leader and takes decisions for her family and her community. And more colours have been added to her list of favourites. She now knows that life comes in different colours and each of them is as beautiful as the others.

Nasima's story may read like a fairy tale. But it is true. Unfortunately there are millions of children whose lives have not been as lucky as Nasima's — because no one reaches them. Many people struggle to communicate about HIV and AIDS within families, especially with their children. They fail to share their status and also the other changes affecting their family. Children on the other hand try to cope with the growing insecurity followed by the realization that something is changing within the family, leaving them wondering why. With most parents preferring to maintain the silence, they unknowingly make their children more susceptible to the changes.

To address this, a child-centered approach has been developed drawing on **Memory Work**. This approach empowers vulnerable children to cope with the changing situation in their lives and fosters a child-friendly environment in families and in communities, free of stigma or discrimination.

Health link Worldwide (est. 1977; Registered Charity England & Wales No.274260), earlier known as ARHTAG, is a specialist health and development organisation working towards improving the health and well-being of marginalised communities in developing countries. It has over 20 years experience in HIV communication and has played a critical role in pioneering memory work in Africa, extending the learning through participatory capacity development. Health link also has extensive experience in supporting participatory initiatives for stigma reduction in Africa and Asia and working with people living with HIV and AIDS. Its work includes participatory social change and behaviour change communication approaches involving vulnerable groups (see www.healthlink.org.uk).

Memory work: empowering families affected by HIV and AIDS

Memory work was first pioneered as a psychosocial intervention for families affected by HIV and AIDS, with children placed at the centre of the initiative. The concept was first developed in 1997 by Barnado's while working with African families affected by HIV and AIDS and living in the UK. It was then introduced in Uganda through the National Community of Women Living with HIV (NACWOLA), with about 25 branches in Uganda. Its interventions involve women living with HIV & AIDS as well as their communities, promoting positive living and empowerment of the women. The women were faced with the dilemma of how to disclose their status to their children. They

needed to be empowered with increased space for voicing their experiences and demanding their rights. They knew their voices were getting stronger but they wanted to reach out to their families as well. NACWOLA and Health link Worldwide began to work together to scale up the initiative in Uganda and other African countries.

In 2003, Health link Worldwide and partners from Uganda, Ethiopia, Kenya, Tanzania and Zimbabwe launched the **International Memory Project** (<http://www.healthlink.org.uk/projects/hiv/imp.html>), supported by Comic Relief, UK. Partners came together, bringing with them a wide range of experiences of working with local communities on HIV and AIDS prevention, care and support programmes. Apart from NACWOLA in Uganda, the other partners included FACT from Zimbabwe, HAPSCO from Ethiopia, Tilla from Ethiopia, Kiwakukki from Tanzania and Kanco from Kenya.

Each of them adapted the approach in their respective contexts and made a significant contribution by integrating it in their other existing programmes. With the experiences of the partners, memory work was shaped as a community-led, child-centered approach that supports families to communicate openly about HIV to strengthen children's resilience and thus the resilience of the families within their communities. The key elements emerging from the interventions include:

- Communication skills
- Child development and parenting
- Disclosing HIV status
- Coping with emotions including loss and bereavement
- Planning for the future and legal support.



The music of love, the music of power within

It helps to nurture a safe environment where disclosing one's HIV status and open communication is possible and encouraged. It enables children to cope with the impact of HIV, understand what support and care is available and develops life skills which empower them to support their parents in caring for the present and planning for their future. Involving children, parents, guardians and service providers as well as the wider community, memory work ensures a holistic and sustainable response to the impact of HIV.

An important part of this approach is the **memory book**, a simple and often innovative tool to support parents and children to communicate about their family history and their memories, leading to a strong sense of identity and belonging. It is to be noted that this process is most effective when applied as part of a comprehensive approach rather than in isolation. The content is always decided by the individual (or family) and one can be very innovative with writing, drawings, collages, mementos, photos and other belongings. It contains memories of childhood, important information about family and friends, parents' beliefs, ideals and hopes for their children, traditions and special events in the family. It can also contain information related to the health of family members, helping to communicate a family member's HIV status to a child. Some families have also developed **memory boxes** containing mementoes which are valued by the child and family. A memory book cannot protect children against loss and separation, but it can help them understand the past and know their parents, as well as preserve the good memories of togetherness.

So far nearly 11,000 people have been involved in sensitisation activities across the participating countries and over 2000 children, parents, guardians, carers and community volunteers have been trained in memory work approaches.

The partners reflected and analyzed the key changes brought about by the interventions by applying the Most Significant Change (MSC) methodology. This is a qualitative approach to assess the impact based on a process of collating and analyzing narratives of change at different levels. The key findings reflect:

- Memory work has strengthened communication within families, especially with children, thus creating a strong support for people living with or affected by HIV and AIDS.
- It has developed the life skills of the children, building their resilience to HIV and AIDS and strengthening peer support to help cope with the situation.
- Parents and care givers have demonstrated increased empowerment in positive living and child development.
- It has influenced adherence to HIV and AIDS treatment and access to other related health services. This is because memory work contributes to reducing stigma and discrimination and helps to create a supportive environment in the family and community, encouraging PLHIV to access treatment.
- Community based organisations have achieved greater awareness of their capacity as agents of change.

- Children's participation in family and community decisions has been valued more as a result of memory work.

Adapting memory work in India: Indian Initiative of Child Centred HIV and AIDS Approach (IICCHAA)

I. The country situation

IICCHAA, adapted from the International Memory Project, was first piloted in India in 2006 by the partnership of Health link Worldwide and Child In Need Institute (CINI), drawing on Health link's years of experience working with partners in Africa.



In 2006, UNAIDS estimated that there are 5.6 million people living with HIV in India, which indicated that there are more people with HIV in India than in any other country in the world. However, in 2007, following the first survey of HIV among the general population, UNAIDS and National AIDS Control Organization (NACO), India confirmed the number as 2.4 million (UNAIDS Epidemic update 2007). This puts India behind South Africa and Nigeria in terms of number of people

living with HIV.

In terms of AIDS cases, the most recent estimate comes from NACO's August 2006 data, showing the total number of AIDS cases reported as 124,995. Of this number, 29% were women, and 36% were under the age of 30. These figures are not accurate reflections of the actual situation though, as large numbers of AIDS cases go unreported. Overall, around 0.3% of India's population is living with HIV. Despite the seemingly low rate, the huge population of India indicates that the actual number of people living with HIV and AIDS is quite high.

In this situation, children have been among the worst affected populations. Their dependence on others has made them vulnerable not only when they are infected with HIV, but also when someone in their family, especially a parent, is infected with the virus. Nearly 70,000 children are living with HIV and AIDS in India (NACO, 2007), and almost a million children have lost one or more parents (Human Rights Watch, 2004). These numbers are increasing. By 2010, the number of children worldwide who will lose one or both parents due to HIV and AIDS is projected to reach 25 million (USAID website, 2005).

The epidemic of HIV and AIDS is a growing threat to children as their economic, physical and social well-being becomes uncertain. As parents struggle to disclose their status to their children, an enormous uncertainty and instability is created within the family. This, coupled with the existing social stigma and discrimination, can lead to a denial of children's basic rights to nutrition, health, education and protection. And like other children, they can rarely exercise their right to voice their needs and concerns. They are always treated as minors who cannot take responsible decisions

With the alarming rise of infection among the general population, the impact of the epidemic on vulnerable groups such as women, children and youth was soon apparent. With support from DFID Challenge Fund, memory work was introduced in India through **IICCHAA**. As the word ‘IICCHAA’ implies “**wish**”, the effort was meant to create a response that aimed at empowering families to fulfill their wish of ensuring better lives for their children. In this process, IICCHAA focused on addressing the psychosocial needs of the children partly because they are more difficult to identify and respond to in a way that is effective, and culturally appropriate.

IICCHAA was initiated as a one year pilot programme in 2006 with the goal:

Key Objectives

- 48

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- Improving communication between parents living with HIV and AIDS and their children in terms of disclosing HIV status and other related information.
 - Enabling parents to make succession plans to safeguard the future of their children.

2) Enable children to cope with changes by:

- Generating awareness amongst the children on HIV and AIDS enabling them to take proper care of their parents, their younger siblings and themselves.
- Building individual skill in expressing themselves through innovative memory games.
- Forming children's clubs/play groups to create space for sharing their experiences.

3) Mobilise community based groups to support the implementation of the initiative as a means towards sustainability by:

- Forming support groups of parents living with HIV and AIDS, guardians and primary caregivers, local service providers, local health authorities, members of local self-government (panchayat) and other stakeholders.
- Building capacities of community support groups to facilitate the integration of the child centred approach as part of a societal response to HIV and AIDS.

4) Develop linkage with government systems, civil society bodies, NGOs, various networks of Positive people, and faith based organisations to create a supportive environment ensuring child friendly services by:

- *Assessing and analysing the impact of work, and documentation of best practices.*
- *Disseminating learning through learning forums.*
- *Advocating the integration of the child-centred approach within the comprehensive HIV & AIDS intervention.*

Geographical coverage: With the project being a pilot initiative in India, special care was taken to select implementation sites from both rural and urban belts so that the intervention could help to test if the approach can be replicated in different situations and contexts. India is a sovereign country having several sub-national regions or provinces called *states* with certain domains of power which cannot be over-ruled or vetoed by the national government. Three such states, West Bengal, Jharkhand and Madhya Pradesh, were selected. While the first two are situated in the eastern part of India, Madhya Pradesh is based in the middle of the country. In each of the states, one urban and one rural area were identified, respectively.

The partnership

Health link Worldwide and Child In Need Institute (CINI) collaborated in this pilot. CINI (www.cini-india.org), founded in 1975, is a national NGO in India, reaching about 1.5 million people (directly or through partnerships). It works for "Sustainable development of health, nutrition and education of children, adolescents and women in need". Since 2002, CINI has coordinated several key programmes on HIV and AIDS

including memory work in India through its HIV and AIDS unit, *CINI Bandhan*. Other key initiatives include capacity development of rural medical practitioners in West Bengal, and training of medics, paramedics and civil society organisations on effective care for people living with HIV and AIDS in Jharkhand. It is also currently facilitating a leadership development programme for the members of positive networks in West Bengal.

Healthlink Worldwide and CINI has worked together for over 10 years on various programmes to raise the voice of vulnerable groups. It is a mature partnership based on trust and mutual respect. When they **initiated the first phase of the Indian Initiative of Child Centered HIV and AIDS Approach (IICCHAA) in 2006**, they brought together the learning of Healthlink from over 10 years experience in child-centred HIV and AIDS projects including memory work with the African partners and three decades of CINI's experience in comprehensive child development initiatives. IICCHAA adapted the learning to an Indian context, giving shape to an evolving model of comprehensive child centred approaches to HIV and AIDS, and are now building on the substantial success of Phase 1.

While CINI played the lead role in programme management, Healthlink Worldwide provided the overall technical support, bringing in the experience of the last decade. Along with CINI, other regional partners were also identified for coordinating the implementation at other sites. The selection was based on a review of existing organisations working on HIV and AIDS, having experience in community based initiatives and also providing institution-based or community-based service support. In some cases, a previous record of partnership through CINI was also considered and special emphasis was also given to the engagement of people living with or affected by HIV and AIDS, which led to the inclusion of Kolkata Network of Positive People (KNP+). The implementation team was as follows:

- CINI: rural site of West Bengal
- Kolkata Network of Positive people (KNP+): urban site of West Bengal
- Holy Cross and Sri RamKrishna Sarada Math: rural site of Jharkhand
- Vikas Bharati: urban site of Jharkhand
- Madhya Pradesh Voluntary Health Association (MPVHA) and Kripa Social Welfare Society: two sites of Madhya Pradesh

Population coverage

Primary target groups:

- Children affected by and infected with HIV and AIDS
- Parents and guardians living with HIV and AIDS

Secondary target groups:

- Service providers
- Community leaders, Panchayat (local self government)
- Religious leaders, peer leaders, etc.

- NGOs, networks of people living with HIV and AIDS and other civil society groups.

The total direct coverage of families

State	Rural		Urban		Total no. of people
	Parents	Children	Parents	Children	
West Bengal	17	26	27	40	110
Jharkhand	36	59	7	5	107
Madhya Pradesh	12	22	13	22	69
Total	65	107	47	67	286

Some of the families were identified by organisations already providing care and support services, while some of them had developed linkages with other local service providers and counsellors. In addition, some of the families came forward during the process of implementation. Since the community meetings addressed the need for such a process and encouraged people to come forward to be part of it, the implementation teams had parents contacting them to be part of the programme. For the initial four to five months, the inclusion of new members was encouraged, but after that no new families were included as primary groups since they would have missed the overall process of intervention.

The project team

Two specific teams were developed for the programme. The **implementation team** in each site had:

- **One project coordinator:** coordinating the overall implementation in the respective area and guiding the other team members
- **One counsellor:** communicating with parents and children through home visits and group sessions
- **Four outreach workers:** mobilising community members to support the families affected by HIV and AIDS.

To support the implementation teams, a **management team** was formed including:

- **Project Director:** providing planning and technical direction
- **Programme Manager:** overall supervision
- **Training Officer:** guiding the trainings and finalising the training packages
- **Communication Officer:** guiding the communication process and finalising the package
- **Management Information System (MIS) Officer:** developing plans and tools, tracking the monitoring process followed by the teams and strengthening the management of data generated
- **Documentation Officer:** capturing the key events, the change stories and narratives of the people
- **Admin & Accounts Officer:** managing the overall financial process

Apart from these a State Facilitator and a Technical Consultant were deputed by CINI

in both Jharkhand and Madhya Pradesh to form the link between the implementation and management teams.

Key steps of implementation:

The project had several stages of implementation. An initial joint planning meeting between Healthlink and CINI teams prepared the layout for the whole implementation. Based on the planning and further consultation with other partners, the following were carried out in the **initial stage**:

-
- Participatory needs assessment;
- Identification of key players and allies at different levels including the immediate field with special emphasis on securing community level support;
- Development of programme implementation guidelines based on the findings of the needs assessment;
- Development of training plans and package;
- Development of communication plan and package;
- Development of monitoring guide, and
- Development of a comprehensive documentation plan as the project emphasised capturing the process thoroughly.

With all the basic drafts of the operational guides prepared, the teams then moved on to the **second stage** which involved the capacity development of the programme management and implementation teams. A **training of trainers (TOT)** was organised for the group at Kolkata, the capital city of West Bengal. Healthlink Worldwide facilitated the workshop and brought international trainers experienced in Memory work. The teams participated actively in the TOT while jointly learning about the global and country situation, the basics of child development, the tenets of a child centred approach, parenting skills, improving parent-child communication, basics of HIV and AIDS, positive living, communicating about HIV and AIDS including disclosure, coping with emotions at different ages including loss and grief, planning for children's future, making a memory book to preserve the family history as well as how to document the key processes.

The next step was the field level implementation, which was initiated by the respective teams. The important activities at this stage happened at two levels:

Family level

- Approaching families when they were comfortable and getting their consent to be part of the initiative.
- Developing a list of the target groups using a confidential coding system.
- Developing rapport with the parents through individual counselling at any centre visited by the families.
- When they were comfortable with being visited at home, the counsellor would make home visits to continue the counselling and follow up on the progress. At this stage the counsellor helped the parents to understand the basic needs of their children and explained the importance of memory work to help them

address those needs. Similarly, interactions with children helped the counsellors to understand the child's emotional needs and help them express themselves.

- Gradually, as the families opened up and showed interest in being part of the group sessions, such homogeneous gatherings were organised giving a platform for all to share and learn from each other. The children's group sessions also helped them to develop self confidence as they enjoyed the presence of so many friends.
- Orientations were organised at each stage for parents and children through issue-based sessions. The parents, in an active process of participatory learning, received inputs focusing on the basics of HIV and AIDS, positive living and coping skills, developmental milestones of children at different ages, communicating with children especially on sex, sexuality and HIV and AIDS, disclosing status and enabling children to cope with it, developing memory tools to preserve the history of the family and planning for the future of the child.



A child session on bad touches and good touches

Sessions were run separately for children within 5 -10 year and 10 -18 year groups. For the younger children, sessions were mostly conducted through joyful learning such as creative games, poetry, drama, paintings, rhymes, audio-visual sessions, dance, and songs. The primary aim was to help them communicate and strengthen their relations with others. They would understand how the body functions, what the key components are including the sexual organs, and how disease occurs and one falls ill. These would lay the foundation for introducing HIV and AIDS, explained as a virus affecting the

human body's power to fight diseases. Often this helped lead to a discussion on good and bad touches, helping them to understand when and how they should protect themselves from abusive behaviour from others.

For the older children the sessions were more informative and practical. Coping with the growing pubertal changes, they would have more detailed discussions on internal organs and their functions, pubertal changes and its impact on their lives and other reproductive and sexual health issues more relevant to them. Hence life skills were introduced, helping them to know themselves much better and develop skills in areas of communication, leadership, coping with emotions and decision making. A positive sense of identity developed as they became aware about caring for themselves and others. As they became more sensitised about their bodies, they could understand the basics of HIV and AIDS more easily and would soon find their misconceptions cleared. Explaining the importance of positive living was gradually done to help them prepare for the disclosure and give a more positive response to their parents.

- *Next, as the parents and the children demonstrated increased understanding about the importance of communicating about HIV and AIDS, the counsellor started facilitating the process of disclosure with the families. The counsellor can never do the disclosure as the process has to happen between the parent and the child. However, a counsellor is needed to extend support to help both cope with the situation.*
- *As the parents become able to disclose, communication gets stronger, helping to build the family's resilience to HIV and AIDS. It has been found that after this, the parents shed their inhibition as they no longer suffer from the anxiety of losing their children's trust and respect. This helps them to disclose in the community and become part of the community mobilisation process. The children have the self esteem to cope better and become more responsible and confident.*

Community level

- *Sensitisation meetings were held with some key stakeholders from the community including religious leaders, community leaders, representatives of local self government, members of youth clubs, women's groups active in the locality as well as people living with HIV and AIDS if they are willing to be part of this (which often happens at a later stage). The main purpose was to explain the objective of the initiative and also understand the level of awareness, interest and ownership. Such meetings also help to address the issue of stigma and discrimination around HIV.*
- *Identification of key players and mapping resources in terms of volunteers, other groups sharing a similar cause or willing to provide support, and existing schemes and programmes related to health, education, nutrition and child protection.*

- Meetings with specific groups were organised for further orientation and analysis of people's perceptions and needs. The presence of community leaders, service providers or any other influential member on such occasions helped in creating a willingness to support the initiative.
- After regular interaction and orientation, the outreach worker starts identifying the potential members of the community support groups, who are capable of mobilising the community and sustaining the process of securing rights for the children as well as the families affected by HIV and AIDS. Based on willing volunteers, community support groups are formed and are briefed about their responsibilities which include providing emotional support to families, helping them share their concerns, providing information on services and facilities, mobilising educational, health and nutritional support for the children by approaching other service providers, creating opportunities for families to access income generating schemes as well as advocating for the rights of the families.
- Special trainings were organised to enable the support group members to perform their roles with increased understanding and sensitivity.
- Support group members helped in mobilising community support to form children and parents' clubs, which act as community centres where the informative and other recreational sessions can be organised. As the membership is open for all, the space naturally becomes a platform for mutual sharing and exchange of views and feelings in an environment free of stigma and discrimination. This is a crucial step towards sustaining the process as the community themselves come forward to provide space for the clubs, and other resources are also mobilised to run the clubs. And with the increased responsibility of organising the activities, the members start getting involved and own the programme.



The pages from a child's memory book

Along with the field level activities, the implementation and programme support teams worked together to strengthen linkages with service providers at other levels. Specific initiatives such as forming an advisory board with key members from different sectors and departments, discussion meetings, periodic updates on the progress of the

initiatives and arranging interactions with the communities helped in strengthening the advocacy for integration of this approach in the comprehensive HIV and AIDS programme.

The positive change

An evaluation of the project was undertaken by an external team of specialised personnel. The team visited all sites and conducted a series of meetings with the different groups including parents, children, support groups members and the programme staff as well. They also reviewed the monitoring reports and the resources developed in the programme.

As the project's direct focus was on parents and children, two key findings proved the effectiveness of the memory work:

1. Improved psychosocial wellbeing of children affected by HIV and AID, three key areas were identified to measure this:

- a) Communication skills of the Parents and children,*
- b) Leadership quality and*
- c) Taking care of parents.*

The data showed improved change in all the areas, providing evidence that the resilience of the children had increased, with 25.8% improvement in communication skills, 29% in leadership quality and 35% in caring for parents. Along with these it was also found that open communication between parents and children, sharing of memories of togetherness, having opportunities to take responsibilities, being able to express themselves and participating in family decisions and having a positive environment helped the children cope with their situation.



- 2. Increased empowerment of parents in helping children to cope with changes:** Empowerment of parents was measured in three areas, a) disclosure of HIV status to children, b) preparation of succession plans and c) identifying future guardians for the children. There was 19.84% improvement in the first, 39.32% in the second and an overwhelming 44.64% in the third. Across all sites, the parents' eagerness to save money and try to create future support for children was strongly evident.

Other key areas reflecting a positive change

- The success of the children's clubs in building the initial community response for creating an environment free of stigma and discrimination.
- Active roles played by community support group members in building general awareness on HIV and AIDS and addressing the needs of the children. Special interest was taken by the elected representatives of the locality.
- The memory book was adapted and used by the families, having a positive impact on their lives as they now learnt to cherish their memories. This also became a crucial tool to help disclosure



A memory box of a child with his valuables

The challenges:

Of course there were challenges. There was a difference in the level of success between the rural and the urban areas. In urban areas implementation was more difficult as community support was often not so strong.

HIV and AIDS being a sensitive issue, especially in India where sexuality is also a social taboo, a lot of the families were uncomfortable about being visited at home. The secrecy about their identity often affected the process of disclosure and also approaching communities to extend support to the families. The counsellor had intensive and regular interactions with the families to convince them of its importance. With intensive activities, the project had less time for refresher training or orientation which was important to strengthen the capacity of the teams for whom the approach

was new.

Most important of all, there was a very tight and specific time period for the project, which limited the resources beyond that. It was just 14 months for a large scale pilot to be initiated. Being a new approach in the area, intensive engagement was crucial to develop the operational guidelines and the packages on training, communication and monitoring, and also for capturing the process of each step, which further shaped the guidelines. The teams managed the initial development of tools as well as the overall implementation. And as shared by the communities as well as the programme team, the project seemed to come to an end when the initiative had only just started reflecting the initial results. In some areas further follow up was required to strengthen the process. The partners, therefore, decided to explore more opportunities to sustain this process. At the field level, from the very beginning, communicating about the timeline and mobilising resources through support groups was a crucial strategic step. In this process partners also took into consideration that further project costs would be reduced since the packages have all been developed and specific guidelines prepared. This has strengthened the ease with which the programme can be replicated elsewhere.

IICCHAA second phase: from hope to conviction

Healthlink Worldwide and CINI have been successful in mobilising support for the second phase of IICCHAA, which is currently running in rural and urban areas of West Bengal and Jharkhand and is establishing itself as a replicable model based on the Indian experience. While it primarily focuses on families affected by HIV and AIDS, it also recognises the importance of creating a community support system to enable disclosure both within and outside the family structure. And it is strengthening its efforts to create and sustain a child friendly space where everyone works together to safeguard the basic rights of the child without any discrimination.

About 200 children from 150 families will be directly covered and 100,000 people in adjacent communities will be involved in community mobilisation initiatives. Special efforts will be taken to enhance the capacity of the community support groups to help them lead the process of sustaining these efforts. To extend the learning, sensitisation and capacity development workshops are being organised for key government departments, NGOs, CBOs, positive networks and other institutions working for women, children and people living with HIV and AIDS. It is envisaged that increased involvement of positive networks will lead to the institutionalisation of learning, strengthening people's ability to ensure better care for their children and also raising voices to demand and ensure their rights.

The project now has a comprehensive monitoring framework with specific and measurable indicators. Along with these, other innovative monitoring tools are also being used, such as:

- Most Significant Change methodology.

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- Child-friendly monitoring and evaluation techniques that can help monitor the increase in children's resilience (individual and collective) and children's own experience in the project.
 - Evaluation questionnaires for assessing the effectiveness of the training sessions.
 - A participatory 360 degree monitoring process to assess the partnership between Healthlink and CINI as well as with other implementing partners.
 - Community Score Cards: a process where qualitative indicators of change are developed in consultation with the communities to analyse the quality of the sessions and the interactions with the communities.

Special care will be taken to maintain confidentiality of the primary target groups by programme staff using ethical guidelines and ensuring consent is given before disseminating case studies or photos.

The evolution of Memory Work: child centred approach to HIV and AIDS

The very concept of memory work is constantly evolving. According to some, it is losing its relevance in view of increasing access to ARVs. The point missed is that memory work is not only about death and dying. It highlights the importance of understanding and addressing the psychosocial needs of children affected by HIV and AIDS and creating a future generation with improved resilience and a positive response towards the global epidemic. As it works towards empowering families and communities to encourage more open communication on HIV and AIDS, it paves the way for positive living in a supportive environment where no child is denied their basic rights. It was once hoped and now believed that soon every child will enjoy the same pleasures and privileges in their childhood, in a world with everyone adding more colours to brighten their lives.

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