

SOS CHILDREN'S VILLAGES FORUM



SOS CHILDREN'S
VILLAGES
INTERNATIONAL

HIV/AIDS: Living a positive life



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IMPRINT

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EDITORIAL



Dear reader,

In 2008 I had the opportunity to visit a Family Strengthening Programme in South Africa. What struck me most was that of almost 200 families participating in the programme, only one consisted of a mother and her children: all the other children lived with grandparents, relatives or siblings – mainly on account of AIDS.

Worldwide there are 2.1 million children under the age of 15 infected with HIV¹. SOS Children's Villages helps and supports thousands of AIDS-infected children and their families, as well as thousands of children whose parents have AIDS or have already died from it. In this SOS Children's Villages FORUM we want to throw light on what SOS Children's Villages is doing in this area and learn from the wide range of experiences gained in the individual projects.

At the end of 2008, an international team presented the SOS Children's Villages HIV/AIDS Policy, "Joining the fight against HIV and AIDS". I would like to express sincere thanks to the members of that team!

The articles

The introductory article in this edition describes how SOS Children's Villages became involved in the fight against HIV and AIDS and how its involvement has developed over the last couple of years, and outlines the key principles of our HIV/AIDS Policy. An overview of the policy can be found in the middle part of this edition of FORUM.

On 24 November 2009 various experts met in Vienna for the symposium on "Children and HIV/AIDS in Africa", organized by Caritas Austria. The article "What others think" sets out the key messages of two contributors. What is most gratifying is that much of the knowledge presented corresponds to the experiences of SOS Children's Villages and confirms that we are on the right track.

Uganda is considered to be the model for Africa in the fight against HIV and AIDS. SOS Children's Villages Uganda supports the efforts of the Ugandan government and provides age-appropriate education as well as counselling and treatment in the Family Strengthening Programmes, schools and medical centres. A variety of interventions intertwine and complement each other. The intention is to go beyond the well-known ABC scheme which involves abstinence, being faithful and using condoms to incorporate other important factors such as knowing your own HIV status, changing your behaviour appropriately and living positively.

In the General Comment No. 3: HIV/AIDS and the rights of the child – an annex to the Convention on the Rights of the Child – it says: "The issue of children and HIV/AIDS is perceived as mainly a medical or health problem, although in reality it involves a much wider range of issues. HIV/AIDS impacts so heavily on the lives of all children that it affects all their rights - civil, political, economic, social and cultural." As people tend to forget this, Zimbabwe has developed an integrated programme to guarantee that children and young people grow up in good health and dignity and enjoy living. The Family Strengthening Programme in Latur, India,

encourages families to stay together, whilst working in cooperation with other local authorities and service providers to support people whose families are at risk of breaking up. Along with the Maharashtra State AIDS Control Society and other NGOs, SOS Children's Villages works primarily in the area of AIDS prevention and provides training programmes, counselling and financial assistance for people living with AIDS.

One of the main objectives of the Family Strengthening Programmes and the self-help groups is income generation. The self-help groups were initiated to boost the progress of female beneficiaries of the Family Strengthening Programmes towards self-reliance. In the self-help groups, women save their money, collectively deposit the amount in a bank account and administer loans among group members at very low interest rates.

A particular feature of the HIV/AIDS activities of SOS Children's Villages Guatemala is the so-called "Family Schools" run by SOS Children's Villages: since the programme began five years ago, 400 families, mostly women, have participated in workshops in the family schools. However, not just mothers but also fathers, young people and other family members attend these schools. The emphasis is on prevention and modes of transmission, with the primary focus being preventing transmission from infected mothers to their children. The workshops at the family schools use the so-called "Educación Popular" approach, a methodology in which learning and knowledge acquisition are based on the hands-on experiences of the individuals and the groups themselves.

In Guatemala great importance is attached to cooperation: SOS Children's Villages Guatemala has been involved in organizing two national conferences on the subject of HIV/AIDS, and is also participating in the preparations for the Central American HIV/AIDS congress, CONCASIDA, which will take place in Costa Rica in 2010.

Temirtau, an industrial city of around 180,000 inhabitants in eastern Kazakhstan, is characterized by its high unemployment rate and the highest level of AIDS- and drugs-related deaths in the country. The Family Strengthening Programme strives to achieve two primary goals, namely to empower families to become self-reliant in caring for and protecting their children and to support the community in caring for children and families affected by HIV/AIDS or with alcohol and drug problems.

The main aim of the "Joint Learning Initiative on Children and HIV/AIDS (JLICA)" is to improve the situation of children affected by HIV/AIDS. The organisation is based on four interdisciplinary "learning groups" which have undertaken scientific work in this field. JLICA emphasizes the importance of putting children and their families at the centre of our efforts. General access to medical care must go hand in hand with social security. Only then can we create the conditions that enable those concerned to benefit from prevention, treatment, care and support.

Karin Demuth and Evelyn Winkler are responsible for the content of this edition of FORUM and have edited and written most of the articles. Thank you very much to them and the other authors.

May this SOS Children's Villages FORUM be another step forward on the road to developing a more thorough understanding of HIV/AIDS, the fight against it and the possibilities for living with AIDS.

Yours,



Christian Posch

¹ Source: UNAIDS, www.unaids.org

SOS CHILDREN'S VILLAGES HAS JOINED THE FIGHT AGAINST HIV AND AIDS



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Over twenty-five years into the AIDS pandemic, the impact on children is seen most dramatically in the rising numbers of children and adolescents orphaned by AIDS. It is estimated that over 15 million children globally have lost one or both parents to AIDS. Most of these children live in developing countries, the vast majority of them in sub-Saharan Africa.

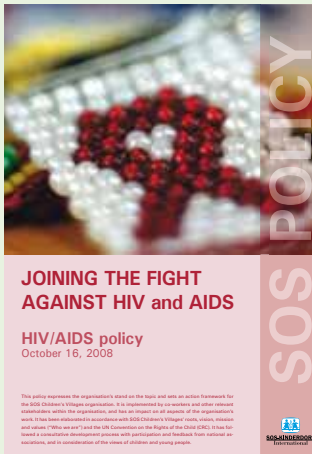
Each one of these 15 million children faces grave risks to their education, health, and well-being: They may have to forgo schooling, there may be less food or clothing for them in the household, and they may suffer from anxiety, depression and abuse.

SOS Children's Villages, globally engaged in the protection and support of children without adequate parental care, started to put HIV/AIDS on its program-

ming agenda in the late 1990s, fuelled by various local, small-scale support initiatives in sub-Saharan Africa. In 2002, a strong global leadership commitment was made in dedicating the prize money of the Conrad Hilton Prize to initiate and fund programmes specifically for children living in high HIV-prevalence communities.

As a consequence, support programmes for children living with chronically-ill parents, children who have lost one or both parents and children living in orphan households in communities affected by HIV/AIDS, were developed in most of the countries of Southern Africa. The development of these programmes was guided by the General Secretariat's guidelines called "HIV/AIDS Framework for Action, 2003". The ex-

The HIV/AIDS policy at a glance:



SOS Children's Villages is committed to unite with children and young people, local communities, other NGOs and the government to fight HIV and AIDS. AIDS is a preventable disease and thus education is key: The first line of action is to ensure that children and young people have access to age-appropriate information and education to make safe lifestyle choices and protect them from contracting HIV. Living with AIDS no longer has to be a death sentence: given appropriate medical, economic and psycho-social support, people living with HIV or AIDS are enabled to live a 'positive' life. Everybody can be infected or affected: all efforts are made to actively work towards reducing the stigma and discrimination which people may face because of their HIV status. SOS Children's Villages supports children, families, communities and governments in taking up joint responsibilities to make AIDS history. (See also page 22)

perience gained and lessons learnt out of these first programmes later contributed significantly to the shaping of the Family Strengthening Programmes which are today an inherent part of the international SOS Children's Villages programme portfolio.



To reinforce the organisation's commitment and in recognition of the devastating effects of the global AIDS pandemic on the lives of children and families, the guidelines were replaced by a global policy on HIV/AIDS in 2008. Acknowledging the fact that to fight HIV and AIDS requires a strong and concerted effort by all local and international stakeholders, the policy was named "Joining the fight against HIV and AIDS". The policy expresses the organisation's position on the topic and sets an action framework. It was developed through a participatory process by an international team, based on external and internal analysis and in accordance with the UN Convention on the Rights of the Child.

With the implementation of this policy SOS Children's Villages takes up its responsibilities as a global player in mitigating the impact of AIDS on the lives of children and adolescents. ■

Evelyn Winkler
SOS Children's Villages International,
Programme Development

WHAT OTHERS THINK

At the “Children and HIV/AIDS in Africa” symposium, organized by Caritas Austria in Vienna on 24 November 2009, various experts met to discuss this topic. Below are the key messages of two of the contributors.

“Meeting the psycho-social needs of children affected by AIDS”

Geoff Foster, physician, HIV/AIDS expert and founder of the Family AIDS Caring Trust, Zimbabwe

Research findings confirm that children orphaned by AIDS are more likely to live in poverty than children orphaned due to other reasons or non-orphans. AIDS orphans are also more likely to have psychological problems. Consequently, effective responses focus not only on psychological help, support and treatment, but also on poverty issues in the form of financial support.

The “Joint Learning Initiative on Children and HIV/AIDS (JLICA)”¹ concludes its final report with some effective key strategies to meet the psycho-social needs of children affected by AIDS:

- Emphasis on family strengthening instead of on child care facilities
- Organization of integrated support services instead of stand-alone material or psycho-social support services
- Planning for long-term interventions instead of short-term projects
- Focusing on normalizing activities instead of on AIDS services (e.g. special after-care, trauma support measures, etc.).

The desired approach is to emphasise “normality”: to be AIDS-sensitive rather than AIDS-exclusive. Fur-

thermore, it is important to strengthen the invisible social network of care, family and community life. Many households affected are able to cope and the responsibility of civil society must therefore be to strengthen these coping mechanisms. It is therefore essential to strengthen the extended family and the community networks. “We have to do a better job of supporting the families and the communities and not just the individual children”, Geoff Foster emphasises.

As scientific research has mainly focused on the diagnosis and treatment of adults there are only very few

“The challenge of early testing and treatment for children living with HIV or AIDS”

Robert Vitillo, Caritas Internationalis

diagnostic tools and treatment options available for children. This is a gross violation of children’s right to life. Caritas Internationalis is currently leading an advocacy campaign to put an end to this situation.

“It is not only a question of quality of life, it is also about the child’s right to life. If children are not treated in time, one third of them will not live to see their first birthday and half of them will not experience their second birthday. Therefore, we must fight to ensure that children have timely access to diagnosis and treatment”, emphasises Robert Vitillo.

According to statistics, around 40% of all adults needing anti-retroviral therapy actually have access to it. For children, this ratio is only 20%. Children are mainly infected through mother-to-child-transmission (about 90%) so the first line of action for children to be protected from an infection is obviously to scale-up and reinforce access to pre-

natal care for women, especially in remote areas. Evidence shows that early and adequate treatment of children can keep them alive and increase their quality of life significantly; however, the challenge lies in early diagnosis. The method of early infant testing that is currently widely available is to test children for antibodies rather than for the virus itself. However, an HIV infection can only be confirmed with a proper HIV-test. A proper HIV-test is currently only done once the child is older than 18 months, because the rapid HIV test can be used as of this age. An HIV-test for younger children, although available, is very expensive and not widely accessible. In the absence of this, many doctors are diagnosing HIV on the basis of symptoms. However, in some countries this approach is prohibited by law.

Another challenge is that many HIV-infected children also suffer from tuberculosis. In this case, science has to invest more in paediatric research to diagnose and treat co-infected children.

SOS Children's Villages is committed to developing programmes that are based on the most up-to-date knowledge and professional exchange. Only then can we meet the challenges mentioned in this article. ■

Evelyn Winkler

**SOS Children's Villages International,
Programme Development**

¹ *The Joint Learning Initiative on Children and HIV/AIDS (JLICA) was an independent alliance of researchers, implementers, policy-makers, activists and people living with HIV. Over a period of two years they dealt with exchanging information, research and learning. The group formally completed its work with the publication of the overall report "Home Truths: Facing the Facts on Children, AIDS and Poverty" in June 2009. See also "For further reference", page 42.*



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PLAIN TALK



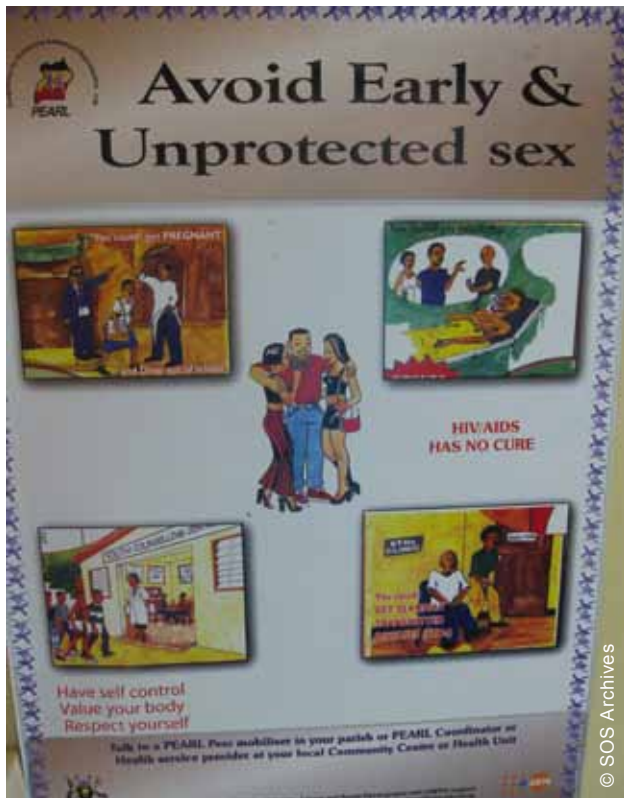
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The government in Uganda takes the fight against HIV & AIDS seriously. SOS Children's Villages Uganda supports these efforts with age-appropriate education and counselling through Family Strengthening Programmes, schools and medical centres.

Uganda is often described as a model for Africa in the fight against HIV and AIDS. The measures taken in the 1990s - government leadership, broad-based partnerships and effective public education campaigns - helped to reduce the number of people living with HIV and AIDS. The perception in society has also changed. People who live with HIV have become more confident and live 'normal' lives. Instead of hiding their HIV status people have now started to speak publicly about it. The number of people who are getting tested is on the rise as well. As there is now an ARV-factory in Uganda, more and more people can afford ART (anti-retroviral treatment) which until now has been very expensive.

The Ugandan labour laws also contain a clear ban on all kinds of discrimination based on HIV status. For instance, someone cannot be denied a promotion: all staff members must be treated equally, irrespective of their HIV status.

Despite all this, the consequences of the pandemic are devastating, be it on a personal, social or economic level. Today, there are currently an estimated 940,000 people living with HIV in Uganda, and a further 1.2 million children who have been orphaned by AIDS¹. Consequently, it is not surprising that SOS Children's Villages Uganda regards HIV/AIDS as a cross-cutting issue. SOS Children's Villages Uganda's activities in the fight against HIV/AIDS range from prevention to



therapeutic measures. A variety of interventions intertwine and complement each other. The ultimate goal is to go beyond the ABC scheme which involves abstinence, being faithful, and using condoms. ABC is insufficient without “D” for “disclosure” which includes knowing your HIV status, changing your behaviour appropriately and living positively.

SPREADING THE MESSAGE

Young people, girls especially, are considered to be a high-risk group for HIV infection. The ultimate goal of any initiative is for young people to adopt safe sexual behaviour and protect themselves from abuse and exploitation. “We see it as our prime responsibility to create HIV/AIDS awareness in every child and family, who we try to reach through different channels and peer groups,” explains Caleb Magara, director of the SOS Children’s Village in Kakiri. “We are just learning that children, youths and adults share different interests in discussing particular AIDS-related issues. Currently joint HIV/AIDS information sessions are held for adults and youths at the medical centre. How-

ever, we felt that young people sometimes felt rather uncomfortable with this, so plans are underway to set up a specific Youth Centre, so that we can provide age-appropriate and youth-friendly services.”

Talking about rather sensitive issues such as your body, sexuality and life-threatening diseases requires a secure environment. For most children this is their family. Caleb Magara: “Most of the awareness raising is done in an informal way in the families: the mothers talk about it with their children in the course of regular family chats and they tell stories because children tend to listen more if they are told stories.” This implies, of course, that adults are knowledgeable on these topics in the first place. That’s why all staff members and carers in the various projects are given regular training on AIDS-related issues.

As much as it is important for children to learn about HIV/AIDS and AIDS-related issues within their family, it is equally important for them to get the message from experts, like medical doctors and teachers, or from people living with HIV or AIDS: as Mr Magara puts it, “Sometimes children listen to these external people more.” Therefore it is part of the job of the SOS medical centres to host regular activities, such as so-called “medical camps” which aim to reach out to a large number of people. They create awareness, promote protection, offer counselling and testing; but they also organise smaller-scale workshops for information and exchange on the topic in a more personal setting. Because of physiological reasons as well as due to the particular social, economic and legal disadvantages they suffer, girls and women have increased vulnerability to HIV infection. Therefore, strong emphasis is placed on tailoring preventative measures specific to their needs.

Raising HIV/AIDS awareness in younger children is closely tied to general health education and safety precautions. Some of the main messages are: “If you get into an accident, do not touch blood”. “Do not have sex as a child”. “Do not share razors and safety pins” [Note: razors are often used to sharpen pencils]. “Avoid getting cuts when playing”. Such health talks form part of the curriculum in the SOS Hermann Gmeiner Schools and the SOS Kindergartens.

Children develop their own mechanisms for dealing with the information, one of which involves using ‘codenames’. For example ‘SLIM’ – “this person



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has got slim” – refers to the fact that being HIV+ can make you lose weight. However, it is equally important to teach children that not every person who is slim has got AIDS and vice versa: a person can look very healthy and still live with the virus.

The main message for all forms of awareness raising and prevention work is in line with Uganda’s national strategy, namely ABC: abstinence, being faithful and use of condoms, emphasized by the messages to “avoid early and unprotected sex”. When condoms are being given out to young people the counsellor demonstrates how to use them and dispose of them properly.

Norman Cwinyyai, head of the SOS Medical Centre, reminds us that “the flow of information has to be continuous. We are human beings - we tend to relax, we tend to forget. So it is our task to keep spreading the information to the people”.

THE YOUNGER GENERATION TAKES THE LEAD

Children who have access to education are well aware of the responsibilities that they have to themselves as well as to society in making AIDS history. The lyrics of one song underline this: “We are the younger generation, we are crying for our elders. AIDS, AIDS is dangerous, many good people have died.”

The Family Strengthening Programmes in Uganda help and encourage children to establish AIDS Clubs in schools as well as out of school. SOS Children’s Villages organises special training for teachers to guide, advise and support children in forming such a club. These clubs provide a forum where children can speak openly about the impact of HIV and AIDS on their lives and the support they need to effectively protect

themselves and cope with being infected or affected by HIV and AIDS. Furthermore, the clubs are practical ways in which children can actively assert their participation rights. They are empowered to organise themselves, voice their opinions on issues that affect them and make positive contributions to their community. Since the children do not want to keep this knowledge just to themselves, they organise HIV/AIDS outreach sessions in the form of songs, dances, and dramas to reach people in remote communities as well as illiterate people. The club members of the out-of-school peer education club Nakyerongoosa² meet on a weekly basis. Active

positively. It is vital to create trust among the young people and provide a space for honest exchange as well as recreational activities. They play games and prepare sketches, dramas and dances for outreach activities within the communities.

When asked about his personal motivation for getting involved, the club leader says: "I have enjoyed the training organised by the Family Strengthening Programme so much, I benefited a lot – I want to become like the trainer and talk to others about HIV and AIDS. Every family is affected and we want to stop AIDS. I want to make a difference and fight some of the myths." One of the most prevalent myths is still



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participation is high on the agenda of the club's principles. As such, every week a different club member prepares to speak about a particular topic and leads that particular session. This way, everybody gradually becomes a good peer educator. The range of discussion topics is wide. They do not talk only about HIV and AIDS but also about other issues that concern them, such as job-finding skills and opportunities, getting married, relationships between boys and girls, how to care for someone who is HIV+, and how to live

that if you have sex with a virgin you can be cured of AIDS or that the virus sleeps at night, so if you have sex at night, you cannot become infected.

One of these HIV/AIDS peer education clubs in a school in Kakiri has an "official" structure, including a Core Committee consisting of a chairperson, a treasurer, a secretary, and other members. When asked about their future vision for the club, the chairperson answers that they hope to recruit more club members from the lower age groups, as currently they only

THE FOUR STEPS FOR VOLUNTARY COUNSELLING AND TESTING

Getting an AIDS test cannot be a quick fix. The particular situation of each individual is approached and considered sensitively, as is the fact that the results of such a test might have substantial life-changing consequences. At SOS Medical Centres the steps for voluntary counselling and testing follow a defined scheme:

- 1** After checking in, the patients go to the waiting area which is equipped with educational videos and brochures.
- 2** Pre-test counselling is done individually, together as a couple, or as a family. This session is primarily used to discuss the implications of being HIV+ or HIV- with the person involved, but usually other related issues such as relationship issues, pre-marital counselling, violence and sexual history which might have brought the person to do the test are also discussed. At the end of the session a contract of acceptance for doing an HIV test is signed. Experience shows that about 90% of those who go for the pre-test counselling do the actual test.
- 3** The actual test, which is conducted in the laboratory, takes about 10 minutes for the results to be shown (= rapid test method).
- 4** The test results are given in a post-test counselling session. If a person is found to be HIV+ he/she receives information and advice about the next medical as well as practical support measures to be taken. Great emphasis is put on the principles of “positive living” including a balanced diet, regular exercise and enjoying relationships. If a person is found to be HIV-, information is given about the “window-period” of three months which means that if the person was infected within the last three months, the results might not show yet. The person involved is advised to come back and do another test in about three months time, just to be sure. Post-test counselling is also used as an opportunity to inform people on how to stay HIV-.



have members between 9 and 15 years old. Also they would like to be more creative, for example designing and producing HIV/AIDS awareness posters, writing poems and organising more outreach activities that deal with AIDS and its related problems.

DO YOU KNOW YOUR STATUS?

Voluntary counselling and testing is being mainstreamed through all SOS Children's Villages projects. Mr Norman Cwinyai, head of the SOS Medical Centre in Kakiri and his team ensure that the necessary infrastructure, materials and skills are in place to provide voluntary counselling and testing services in-house, but also to organise outreach programmes and "mobile testing services".

A person whose test result is positive is given an information pack on the further steps that need to be taken: for example, where and how to access anti-retroviral treatment if needed, how to adapt your diet and lifestyle in order to live "positively". People are informed on human rights, in particular with regard to non-discrimination.

To offer this holistic support for people living with HIV or AIDS, the SOS Medical Centre works closely with other SOS projects and local and national partner organisations.

For instance, all children in the schools that SOS Children's Villages is running or cooperating with are counselled and encouraged to get tested. Recently 130 children of the SOS Hermann Gmeiner School Kakiri were tested and it was very encouraging that only one child was found to be HIV+. The family situation of this child was assessed and appropriate care and support is now being provided through the local Family Strengthening Programme.

The general philosophy is "plain talk", which means discussing issues concerning sexuality openly. Of course, this is a sensitive issue and sometimes people are ashamed to tell the truth. Yet it is necessary to talk about it. Mr Cwinyai is convinced that HIV/AIDS counselling always includes talking about "life skills", for example how to cope with stress and pressure or how to relate to peers. He also finds that young people are generally less stressed than elder persons if they are found to be HIV+. "They are more informed, they have access to ART and they know that they can continue with their studies. They see themselves as 'healthy' - being HIV+ is no longer seen as a death sentence."



“Just like any other child”

Goreth and Kezia, two SOS Children's Village mothers from Kakiri, talk about HIV/AIDS and its implications for life in an SOS family.

FORUM: HIV/AIDS is a big issue in Uganda. How do you address the topic in your family?

Goreth: You have to talk to children differently about sexuality and HIV/AIDS. You have to take the character of the child into account. Children come from different backgrounds. Some of them have been watching adults' films and have been engaged in sexual activities, others are still completely innocent. A mother has to be very observant in relation to every child, for example the type of language a child uses, and what games she or he plays. The main message for the children is that the life of an adult or a child operates according to very different realities. It is good that they are experiencing right now the wedding of two sisters and we use this as the basis to talk to the children about the 'right or-

der' in life: "First you finish school and get a job, and then you find yourself a boyfriend and get married". We also use educational films in the family home and we take preventive measures within the family, like putting name tags on razor blades and toothbrushes. And we tell them to 'fear' blood.

Kezia: We also talk to children about the possibility of children being HIV+ through mother-to-child-transmission. I can tell you the story of Jim, a 12 year old boy from the SOS Children's Village. After discussing this topic, he went all by himself to the medical centre to get an HIV/AIDS test to know his status. Since then he has campaigned for every child in his school and in the SOS CV to get tested.

FORUM: In your families, are there any HIV-positive children?

Kezia: I have a 9-year-old girl in my family who is HIV+. She knows that she is not as strong as other children, that she has to drink a lot and that she has to take a tablet every day to strengthen her immune system. She also knows that she has to go to the clinic if she runs out of tablets. I always make sure she is never exposed to cold and give her less 'difficult' household chores. However, I think it is important that she is not 'favoured' in any way. I treat her just like any other child who has a particular medical condition.

In terms of diet, we do not prepare special menus for children living with HIV. We generally have a balanced menu for all children in the family.



To ensure utmost care and support of children, they are also given information and encouraged to find out their status. According to Ugandan legislation, children from the age of 12 can get a test without the consent of their guardians.

Mr David Yiga, VCT counsellor of the SOS Medical Centre is strongly convinced that children have a right to know the truth about their health status. “When counselling children, I talk in a child-friendly language. However, the same level of confidentiality has to be kept”. He admits that sometimes revealing the HIV status to a child can be difficult, especially in a situation where the mother does not want to reveal the HIV+ status to her child.

CARE AND PROTECTION BEYOND MEDICAL TREATMENT

“Children living with HIV need to have a supportive environment including appropriate hygiene measures, a balanced diet, and stable relationships - all aspects that contribute to strengthening the child’s immune system”, says Mr Magara, director of the SOS Children’s Village in Kakiri. As much as it is important for people infected with HIV to receive adequate medical treatment, support needs to go beyond that and include economic, psycho-social, medical and legal support. In particular children who are living with the virus need comprehensive support according to each child’s individual physical status.

Measures to protect children affected by AIDS include, in particular, interventions to prolong HIV-

positive caregivers’ lives and improve the families’ living standards so that they can adequately care for their children. This is also the main credo of the Family Strengthening Programmes in Uganda. The goal is to address every aspect of a child’s healthy development including education, health and care through strengthening and empowering their caregivers.

Schools also have an important role to play in this. They are to be seen as partners to ensure that each child develops holistically. “The teacher”, says Joseph Wanyama, the principal of the SOS educational facilities in Kakiri, “creates conditions to facilitate learning, not only teaching.” This means that, for example, children are given food at school to ensure that they can concentrate. Children may also have to ask for some time off school to care for their sick parents or relatives at home. In this case, the school intervenes on behalf of the children to look for other support options, such as support through the SOS Family Strengthening Programme or through organising remedial classes for children to address individual learning needs.

The following family story shows how care and awareness raising need to go hand in hand. Two children were living with their auntie because their parents had died of AIDS, and the children were also found to be HIV+. The auntie did not send them to school because she believed that they would die anyway. When the family got support through the Family Strengthening Programme the misconceptions about living with HIV could be resolved and the children were supported through remedial classes to attend regular school. They were given proper medical support. Today they are energetic and one can hardly tell that they are HIV+.



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FIGHT STIGMA AND DISCRIMINATION

When asked about stigma and discrimination David Yiga and Norman Cwinyai from the SOS Medical Centre express a somewhat different opinion from that of most people: “It is still there,” they say: “And therefore it is important to keep information confidential. A lot of people are still reluctant to be open about their condition”. Not far from the SOS Medical Centre are barracks for soldiers. Although the barracks have their own VCT (Voluntary Counselling and Testing) centre many soldiers come to the SOS Medical Centre to be more ‘anonymous’ when being tested.

The advantage of the SOS Medical Centre is that VCT services are integrated within the regular medical services. If people are seen entering the building, they are not automatically suspected of going for an HIV/AIDS test. People do not want to be associated with being HIV+ because there is shame attached to it – as there is with being bankrupt, for example, which is not a comfortable status to share with others either.

It’s the variety of provision and the fact that all the different support programmes work closely together that makes the work of SOS Children’s Villages in Uganda especially efficient. Jointly they want to achieve one and the same goal: to prevent HIV infection, to fight stigma and discrimination, and to provide protection and support for children and families affected by AIDS. ■

Karin Demuth, Evelyn Winkler
SOS Children’s Villages International,
Programme Development

We would like to thank all staff members of SOS Children’s Village Uganda who have taken time to talk about their work.

- ¹ UNAIDS (2008): Report on the global AIDS epidemic
- ² Parish in Kakiri, where SOS Children’s Villages is supporting a Family Strengthening Programme

ALL OUR RIGHTS



SOS Children's Villages Zimbabwe has set the goal of supporting its target groups affected by HIV/Aids to call for the rights they have been deprived of. This not only includes supporting adults in fulfilling their tasks but also empowering children to claim these rights more effectively.

Zimbabwe is among the countries worst affected by the global HIV pandemic. Although according to current estimates, Zimbabwe has experienced a significant decline in HIV prevalence from a peak of 29.3 per cent in 1997/98 of 15.6 per cent (2007) among the adult population¹. However, between now and 2018 the infected number of people will remain near 1.8 million if HIV prevalence stays high. Adults account for more than 90% of all infections, while children make up 7% to 9% of the infected population. Although the country's population is decreasing, the number of HIV/AIDS orphans is growing.

In response to this crisis our SOS Children's Village model becomes more relevant. The main challenge in

running our programmes and service is to shift from the welfarist approach to a rights-based approach.

MISSION AND STRATEGY

The work of SOS Children's Villages is carried out with reference to the environment in which we are operating. The political, economic and social context of the country is already taken into account at the time of planning. The excerpt from the National Plan 2007 - 2009 below illustrates this point:

“Our priorities must go in two directions: **building** families for Zimbabwean children and **strengthening**

ening Zimbabwean families. Both are important because we believe our model of childcare is the **best** alternative for children who have fallen out of their families and extended families. Strengthening families is important because of the unique social environment of Zimbabwe, which has been devastated by HIV/AIDS and therefore needs our support.”

SOS Children’s Villages supports children on two levels by:

- building a safety net for those children who have fallen through the safety net of the nuclear and the extended families
- helping children in the community who live in their original family (e.g. grandparents, single parent, extended family or sibling-headed family).

RESPONDING TO CHILDREN’S RIGHTS

Our vision, that every child belongs to a family and grows up with love, respect and security, has generated systematic approaches in analyzing the ways in which children’s rights could be violated, especially in the HIV/AIDS context. The services of SOS Children’s Villages Zimbabwe support various target groups in claiming the rights they have been deprived. Now it is essential to support the duty bearers in fulfilling their responsibilities, as well as to empower children as rights-holders to claim their rights more effectively. The General Comment No. 3: HIV/AIDS and the rights of the child – an annex to the Convention on the Rights of the Child – has a closer look at this issue. It states:

“The issue of children and HIV/AIDS is perceived as mainly a medical or health problem, although in reality it involves a much wider range of issues. The right to health is central. But HIV/AIDS impacts so heavily on the lives of all children that it affects all their rights, either civil, political, economic, social and cultural.

The rights embodied in the general principles of the Convention - the right to non-discrimination (art. 2), the right of the child to have his/her inter-

est as a primary consideration (art. 3), the right to life, survival and development (art. 6) and the right to have his/her views respected (art. 12) - should therefore be the guiding themes in the consideration of HIV/AIDS at all levels of prevention, treatment, care and support.”

The target groups for family-strengthening are orphaned and vulnerable children (double and single orphaned children living in difficult circumstances), children of terminally ill parents, guardians and children who have compromised health. They live in households headed by grandparents, single parents, uncles/aunts, siblings, relatives or people that are not related at all.

Most of the families are unemployed or have a very low income and survive on informal trading. The families are characterized by large extended families who most often live in crowded homes, frequently suffer from illness, have high mortality and mobility rates. Unmet psychosocial issues and needs frequently lead to abuse.

The overall goals of our programme are to ensure:

- the survival, protection and healthy development of children and the reproductive health of adolescents
- that children acquire basic learning skills in order to help them realise their full potential and contribute to their own and family development
- that children live in secure, safe and healthy homes
- an increase in food security and family disposable income to enable families to improve their children’s welfare

The services offered are the following:

Health: Health measures include access to treatment and medication at local clinics and pharmacies and referrals to hospitals and dental clinics, herbal and nutrition gardens, food packs, referrals to other organisations like Africare, personal and environmental hygiene programmes, home visits and home nursing. This should lead to an improvement in household nutrition status, availability of cheaper alternative remedies and an increase in skills of coping with loss. Over the years there has been a good response to opportunistic infection treatment. There has been a decrease in



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the number of children visiting the clinic and an enhanced capacity to respond to illness. Response from trainees is that their enhanced skill base supports them to help the sick confidently.

For children living in an SOS family, the following concrete steps are taken:

- The children's HIV status is assessed after admission
- Infected children are put on specialist health services
- A consultant nurse was recruited to assist village children and young people
- Co-workers are trained to support children on ARV
- Immunizations are monitored

Psychosocial Support: Children have the right to a stable emotional well being. We therefore offer life skills workshops covering information on HIV/AIDS, reproductive health, grief work, self-esteem, confidence building, provision of counselling by school teacher representatives and community representa-

tives. The information base is enhanced as well, though it is difficult to change people's behaviour.

Among our activities are: workshops for staff on counselling and care giving, training children in peer counselling, provision of counselling to children and youth with specific challenges, referring children to specialists in clinical counselling, participation in sporting and cultural activities. The impact we want to achieve is improved emotional well being, development of self-esteem and empowerment, confidence building and participation - voices of children are heard and they develop their skills and their self-identity.

Legal Support and Culture: This includes recreational therapy through participation in clubs and games, linking children with legal service providers. With loss of parents to HIV/AIDS, children lose their legal well being. The positive impact of the service is a wide information base and an enhanced capacity to link up and correct issues.



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Referrals to other service providers ensure that beneficiaries have access to specialist services such as counselling, home based care and free legal services.

Entrepreneurship and Food Security (Livelihood):

This includes income-generating projects, food production, poultry, and homemaking skills. We strive for increased opportunities to boost household income through projects, increased opportunities for guardians to save household income through homemaking skills and doing handicrafts. Family disposable income has slightly increased, for example, through uniform making.

The above services and programmes are offered irrespective of children's gender, religion, ability and HIV/AIDS status. As for the HIV+ children, they are given ongoing support which includes counselling, access to care and medical treatment. Caregivers are equipped with skills to become effective caregivers and treatment supporters.

TOGETHER WE ARE STRONG

Alliances with governmental and non-governmental organizations are essential. Some examples: On the operational level, the co-operation with the Department of Social Services is helpful when it comes to the admission of new children or the process of identifying documents, whereas Population Services International (PSI) gave us advice in regard to the HIV/

AIDS Workplace Policy and on HIV/AIDS awareness and training.

In addition, we offer a psychosocial support programme, which involves the training of SOS mothers and other co-workers to provide the necessary support for the children. Children are also given information on HIV/AIDS to enhance awareness, which will ultimately result in behaviour change. Other support systems such as the Victim Friendly Unit from the police on crime awareness and children's rights as well as Childline, an emergency number for abused children, have been involved as well. The children are also involved in awareness activities in the community as evidenced by their participation in the United Nations Day on Children's Rights and Child Protection.

Because of HIV/AIDS, children are not safe, not protected and do not have ongoing support of their parents. Children lose property upon the death of their parents and poverty deeply entrenches itself in the family, as breadwinners die and the pressure is on the very few elderly who are also not well. Home visits rise our awareness of children's situations and also act as an evaluation tool to assess the impact of our interventions with regard to HIV/AIDS and other related activities.

On the socio-political level we try to promote positive developments by working together with partners, e.g. with the Ministry of Education, with a link teacher at each school in our area of operation. We have managed to embark on block granting, training of link teachers and a careers day and to organize a prize giving day

Continued on page 25



**SOS CHILDREN'S
VILLAGES**
INTERNATIONAL

AN OVERVIEW OF THE SOS CHILDREN'S VILLAGES HIV/AIDS POLICY

WHAT WE STRIVE FOR

SOS Children's Villages recognises the devastating effects of the global AIDS pandemic on the lives of children and families and promotes full respect for and protection of children and family members' human rights irrespective of their HIV status. We believe that AIDS is a preventable disease and thus commit ourselves to the participation of children and young people, to create and maintain a supportive environment that reduces the vulnerability of children and their carers to HIV infection. We put all our effort into programmes that enable children orphaned and made vulnerable by AIDS to grow up in a caring family, have equal access to education and other essential services, and be protected against stigma and discrimination. We work in partnership with others to strengthen community-based responses and advocate for stronger national and international commitment to meeting the needs and rights of children growing up in communities affected by AIDS. In all our activities we involve children and young people, as they are key to the response to the epidemic.

TARGET GROUP

- Children living with HIV
- Children living with parents, relatives or caregivers who are living with HIV
- Orphaned children, including children living in child- and sibling-headed or grandparent-headed households
- Children living in households that foster orphaned children

PRINCIPLES GUIDING SOS CHILDREN'S VILLAGES' ACTION

- 1** Effective measures to prevent HIV infection among children, young people and carers are integral to all programmes implemented and supported by the organisation.

JOINING THE FIGHT AGAINST HIV AND AIDS



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2 All SOS programmes, from service delivery to advocacy, actively work towards reducing the stigma and discrimination which people face because of their HIV status.

3 Protection and supportive measures for children and families affected by AIDS are built into SOS programmes to reduce the burden on children's lives and to improve their chances of survival and development.

4 The involvement of children and young people is key to the response to the epidemic. They are empowered to take a leading role as advocates and educators, and they participate in developing, implementing and evaluating programmes that address them. Children's views are heard and given due weight in all decisions that affect their lives.

5 Partnerships with key stakeholders allow for strong and concerted responses to children's and families' needs and increase the accountability of those whose responsibility it is to respect children's rights.

SEEING THINGS THROUGH THE EYES OF A CHILD

Although we cannot provide for all of children's needs, it is important to listen to what children have to say. Looking at our work in Zimbabwe from the child rights' point of view, we found out the following:

Aspects of Children's Rights	Children's voice concerning these issues
Right to Food	<ul style="list-style-type: none"> ■ Children appreciate the distribution of food, which was their number two priority in the needs analysis. ■ Children thought that items like rice, cooking oil, soap, vaseline and peanut butter should be included in the food assistance package.
Right to Health	<ul style="list-style-type: none"> ■ Children's voices are being heard in meeting general health needs but there are certain issues that are not met, e.g. access to ARV therapy, specialist treatment, i.e. eye specialists and medicine since the pharmacy is too far.
Right to Shelter	<ul style="list-style-type: none"> ■ To a limited extent, assistance has been offered to improve accommodation. Children want to live in habitable and secure homes. Neither children nor the organisation have control over some of the issues related to shelter. However, some have been assisted through the Justice for Children Trust.
Right to be Heard and Right to Participation	<ul style="list-style-type: none"> ■ Children participated in the needs analysis at the start of the programme. ■ Children participate in quarterly and annual reviews and consultative meetings. They complete child assessment forms and express their views in the language they understand best. ■ Participation in "Day Against Child Abuse", Global Peace Games. Children have indicated for a long time that they want to play games. ■ Different methodologies have been used to encourage child participation, i.e. through drama, writing and training clubs.



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for orphaned and vulnerable children, to advise and identify children in need of exercise, books and uniforms. Working together with the city of Harare has had the effect that they offered venues for distribution and meetings with the community. On the level of NGOs, our partners offer counselling training, information on psychosocial issues and family therapy as well as free legal representation for children on children's rights such as birth and death certificates, estates, abuse and maintenance.

THE ROLE OF EDUCATION

Under the title "The role of education" the General Comment states:

"Education plays a critical role in providing children with relevant and appropriate information on HIV/AIDS, which can contribute to increased awareness and better understanding of this pandemic and prevent negative attitudes towards victims of HIV/AIDS. Furthermore, education can and should empower children to protect themselves from the risk of HIV infection.

In this regard, the Committee wishes to remind States parties of their obligation to ensure that primary education is available to all children, whether infected, orphaned or otherwise affected by HIV/AIDS. In many communities where HIV has spread widely, children from affected families, in particular girls, are facing serious difficulties staying in school and the number of teachers and other school employees lost to AIDS is limiting and threatening to destroy the ability of children to access education." What is SOS Children's Villages Zimbabwe doing? HIV/AIDS education is given to children in the kindergartens through a thematic approach related to safety. Children are taught how to handle situations where they see blood, as well as the meaning of different kinds of physical touching as a way of creating awareness of potential abusive situations.

In schools, the Ministry of Education has introduced AIDS Education as part of the Social Studies Curriculum in order to create awareness on HIV/AIDS and ensure that children are from a young age aware of modes of transmission, signs and symptoms, healthy eating habits and preventative methods. In primary schools, the curriculum has been designed for Grades 4 to 7 (ages 9 - 12) and 30 minutes per week are allo-



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cated to this topic. Children learn through a variety of activities, written exercises, drama, poetry and music. Often schools collect informative posters that are designed specifically for children and young people to put up in classrooms and school notice boards. Due to the limited time available for this topic, some schools have AIDS Action Clubs where children meet for an additional two afternoons a week to discuss the topic: how to cope with peer pressure, general hygiene, grooming and deportment. During these sessions, children and young people have a greater opportunity to discuss issues freely.

Our Secondary School in Bindura also has a Youth AIDS Club led by a teacher with a Degree in Counselling, who trains some of the young people as peer educators. There is also the Kwanatete Club which caters specifically for girls and focuses on teaching of child rights and sexual exploitation with regard to HIV/AIDS. Much of the material used comes from a local NGO, the Girl Child Network, which also provides training to the teachers. These clubs meet every Wednesday from 2.00 pm - 4.00 pm.

However, there is still a lack of suitable material for children. In the kindergartens, educators need to become more innovative in designing material that can be used by very young children, and some of the teachers are still not free to discuss issues relating to sex despite the fact that they have undergone appropriate training in this context.

Consequently, we have to source additional material to cater for the large numbers of children in our schools

and kindergartens. We have to allocate more time in all schools to both staff and children to discuss HIV/AIDS-related issues. In addition, we should involve parents and resource persons from the community in the dissemination of information.

It is our goal to enhance integration of children into the mainstream society by providing formal education at our schools and other community schools, by remedial education provision to academically challenged children, by access to educational resources such as libraries, vocational and tertiary education and by career guidance. The impact we strive for is an increase in self-esteem, confidence and psychological health, socialization and the ability to integrate with other children as well as self-reliance after acquiring vocational and tertiary education and successful inte-



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gration into society. The children's voices are heard when they make choices of what they want to do in life, i.e. in terms of their choice of vocation or profession.

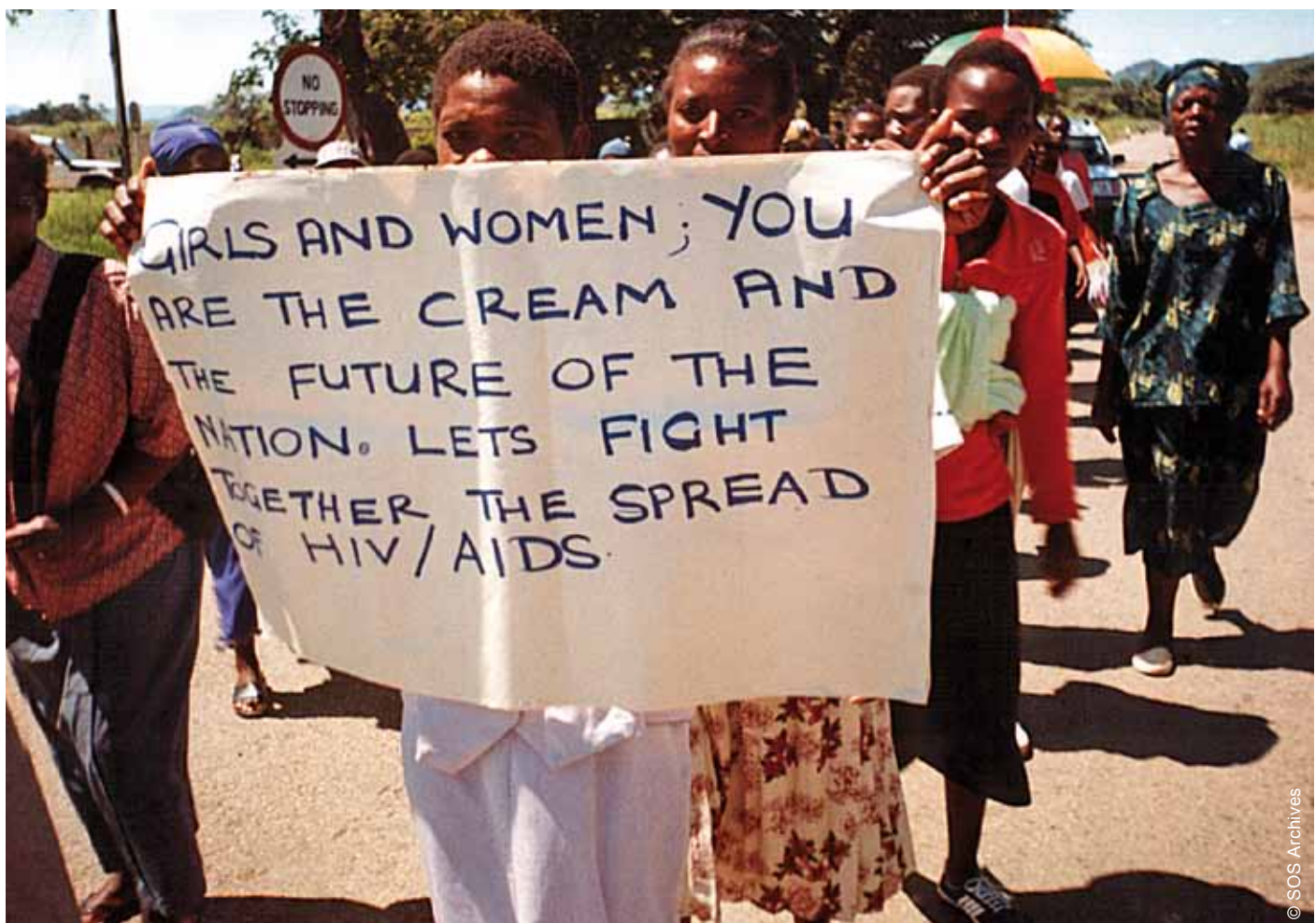
Supporting families of origin includes the payment of school fees and block granting, the provision of counselling by school representatives and community representatives, the provision of school uniforms, careers days, prize-giving days for confidence building and facilitating consultative meetings between the schools and the guardians.

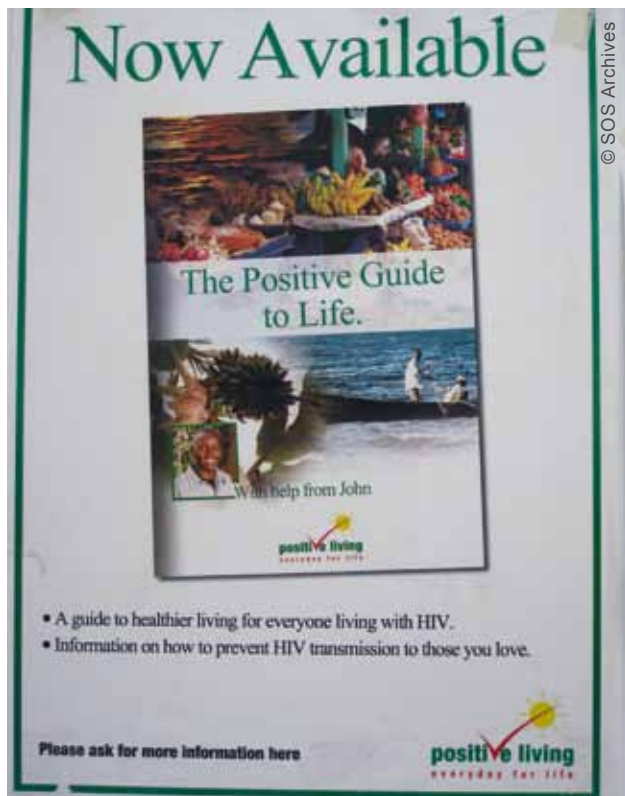
This should result in more opportunities for children to complete primary and secondary school, an increase in children's self-esteem and exam preparedness and an increase in literacy levels among guardians. Young people need better opportunities to acquire vocational and tertiary qualifications. The impact of HIV/AIDS results in high school drop outs, hence payment of fees ensures the enrolment, retention in and completion of schools.

STAFFING AND COMPETENCY

After admission to SOS Children's Villages children go for HIV testing. This is done to guide the SOS mother and other co-workers on how to offer the most appropriate care and support for the child. Those who are recommended for antiretroviral treatment (ART) begin treatment immediately. Those whose tests indicate that their immune system simply requires boosting, receive nutritional supplements.

Mothers and children receive counselling at government or private hospitals to support them to understand their situation and know how to cope. It also provides them with an opportunity to accept and adjust to "living with HIV". SOS mothers and other co-workers have received training in counselling to build their capacity to support each other and the children.





The organisation works with several partners to ensure that children receive the best support. We work with the National Aids Council, where we access material and non-material support. Local hospitals are also strategic partners in the treatment of children with the virus and those affected by HIV related opportunistic infections.

In 2003 and 2004 intensive training, awareness and information on HIV/AIDS was conducted with all staff of SOS Children's Villages Zimbabwe. The training conducted by Population Services International (USAID) focused on developing awareness of HIV/AIDS, developing an HIV/AIDS Workplace Policy and building trust.

The training of SOS mothers includes modules which focus on caring for children who are HIV+. In an effort to strengthen our capacity to deal with HIV/AIDS, staff have registered for an Executive Certificate in Strategic HIV/AIDS Project Management. Furthermore, diploma courses in Systemic Counselling are

being undertaken and a co-worker at the SOS Social Centre in Bindura is studying for a degree in counselling.

The objective of the HIV/AIDS Workplace Policy is to produce a standard policy, which clearly states the organisation's position with regard to HIV/AIDS in the workplace. It aims not only to prevent the spread of HIV and to reduce the stigma and discrimination associated with HIV and AIDS but also to create a supportive environment of compassion and understanding for co-workers with HIV or related illnesses. We want to ensure that all co-workers are treated equally whether they have HIV or not and to provide all staff with the information necessary to increase their awareness of the issues related to HIV infection and AIDS. The HIV/AIDS Workplace Policy contains basic information on the illness and proposes programmes on education, awareness and information such as setting up an AIDS Action Committee in every SOS Children's Village facility or offers in-depth counselling for co-workers and their families. SOS Children's Villages treats co-workers who are affected by AIDS in the same way as any co-worker with another life-threatening illness such as cancer, diabetes or heart diseases. The Workplace Policy clearly states that co-workers with HIV will be productive and healthier for a longer period if they receive the medical, social and psychological support they need. ■

The article is based on the report "HIV/AIDS Policy Development. SOS Children's Villages Internal Analysis Zimbabwe"

Summary: Karin Demuth

¹ International Labor Office Geneva: Finding ways to cope with the HIV impact in Zimbabwe, http://data.unaids.org/pub/ExternalDocument/2009/20090402_ilozimbabwe_en.pdf

WITH MY OWN HANDS

FAMILY STRENGTHENING PROGRAMME

LATUR/INDIA



Sangeeta is 32 years old and has three children. She lost her husband to AIDS in April 2007. After her husband's death she was forced to work as a casual labourer in the local market. But soon she realised that it was difficult for her to work as a daily wage earner. Her health was so poor that she became incapable of carrying out any kind of demanding physical work.

Sangeeta lives within three kilometres of SOS Children's Village Latur. She was identified by the Family Strengthening Programme co-workers and has been supported by the programme since July 2007. During a chat with her in the early days it was found that her health had been declining day by day. She was advised to take the HIV test as her husband had died of the disease. Sangeeta was diagnosed as "reactive" to HIV, so she was given the antibody test by the government AIDS Control Society in Latur. Her children

were also diagnosed as "reactive" and are now receiving the appropriate medication.

TAILOR-MADE INTERVENTIONS

To support Sangeeta and her family as effectively as possible, the Family Strengthening Programme Latur has taken the following steps:

- She was offered life skills training. This type of training gives people the skills that will allow them to change their behaviour: it involves theoretical and practical ways to be happy, becoming physically and mentally fit through the practice of silence, regulated breathing, a balanced diet, sound sleep, positive thinking and music. Additionally, they are shown asanas¹, pranayama², exercises, yoga, meditation and how

to stimulate brainpower and solve problems. This is achieved by activities such as completing unfinished sentences, scenarios, short answers, storytelling, ranking, and role play. Other features of the life skills training module include: a balanced use of air, water, food, sleep, positive thinking, classical music, recitation of Omkar³, communications skills, value analysis and clarification skills, decision-making skills, coping and stress management skills.

■ In collaboration with the local centre of the National AIDS Control Organization, special counselling on HIV was given to Sangeeta. They make sure that she receives professional positive living counselling. Unlike the life skills training which is offered in the form of various courses, “positive living” counselling involves one-to-one guidance, often with an older person held in high esteem in the community.

Positive living counselling includes talking about fears, concerns and problems as well as providing better information about the major signs and symptoms of common opportunistic infections and how they can both be prevented and managed. There are also discussions about ways of living positively and helping to reduce the fear of disclosure of HIV status, stigma and discrimination. This form of counselling also aims to teach people about prevention and risk and re-

education methods, as well as to encourage the use of resources available in the community.

■ Regular counselling is given to Sangeeta and her children by family strengthening co-workers. This includes support in matters like nutrition, hygiene or administrative affairs. Sangeeta’s family was advised to seek anti retroviral treatment from the local government hospital in Latur and the assigned co-worker ensures they are getting the correct medicine as prescribed by the doctor.

■ Despite being diagnosed as HIV positive, Sangeeta did not give up but decided to invest in her professional future. The Family Strengthening Programme gave her support in attending a stitching and tailoring course and she now holds a diploma from the government’s Industrial Training Institute. After completing this course Sangeeta borrowed a sewing machine from her sister and started accepting stitching and tailoring jobs from the neighbourhood. Now she earns approximately INR 1000 (around 14 EURO) per month from this work. Furthermore, Sangeeta receives financial support of INR 900 per month from the Family Strengthening Programme Latur. She was also encouraged to find out about a social security scheme for poor widows, so she now receives a monthly pension of INR 200 per month from the provincial government.



OBJECTIVE: PROVIDING GOOD CARE FOR CHILDREN

There are numerous stories like Sangeeta's - they were the impetus for SOS Children's Villages India launching its Family Strengthening Programme in Latur in 2003. The aim of the programme is to support families at risk of abandoning their children and to encourage families to stay together. SOS Children's Villages therefore works with local authorities and other service providers to help families and enable them to take good care of their children. Along with the Maharashtra State AIDS Control Society and other NGOs, SOS Children's Villages works primarily in the area of HIV prevention, organizing workshops, training programmes, counselling and financial assistance for people living with HIV/AIDS.

To reduce discrimination against and the stigmatisation of those who are HIV positive, SOS Children's Villages advocates that government authorities significantly scale up efforts in the area of HIV/AIDS prevention and care. Together with its partners, SOS calls on state governments to provide increased access to voluntary counselling and testing, the treatment of opportunistic infections, universal access to anti-retroviral therapy, and access to basic health, education and social protection services. To improve public attitude and behaviour towards people living with HIV, community-based awareness and education campaigns are organized in cooperation with local groups, such as youth clubs, women's organizations, and schools.

Within the SOS programmes, a forum is provided where children can speak openly about the impact of HIV and AIDS on their lives and receive the support they need to protect themselves effectively and to cope with being infected or affected by HIV and AIDS. Children are consulted and directly involved in the design, implementation and evaluation of prevention and protection programmes in response to HIV and AIDS. A great deal of effort is put into building the capacity of community-based organizations and local governments to respond more adequately to the needs and rights of children and families affected by AIDS.

In addition, the Latur Family Strengthening Programme provides nutritional, educational and health support as well as vocational training, career counselling sessions and job placement support. It aims to



raise awareness on hygiene, child rights and improving people's parenting skills. Families are linked with existing self-help groups; if there is no such group, a new one is formed. Self-help group members are beneficiaries of the Family Strengthening Programme as well as other community members. As income generation and livelihood promotion are the main objectives of the Family Strengthening Programme, self-help groups have been set up to boost the progress of female Family Strengthening Programme beneficiaries towards self reliance. In the self-help groups women save their money and collectively deposit the amount in a bank account in the group's name, administer loans among group members at a very low nominal interest rate to help with the occupational and other needs of members and their families. Group self employment opportunities are planned for the future. Besides, this is the platform where they share their feelings openly. Sangeeta is now able to feed her family. Her state of health has improved, and all her children go to school. There is hope, and there is a future. ■

Karin Demuth

**SOS Children's Villages International,
Programme Development**

We would like to thank the SOS Children's Village Family Strengthening Team Latur for providing information for this article.

- ¹ *Asana is a body position, typically associated with the practice of Yoga.*
- ² *Pranayama is often translated as control of the life force (prana). When used as a technical term in yoga, it is often translated more specifically as "breath control".*
- ³ *Omkar means the recitation of the syllable Aum (also Om), a mystical or sacred syllable in the Indian religions.*

WHO, IF NOT US?



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The biggest success in the fight against HIV/AIDS in Guatemala is the “Law on the fight against HIV/AIDS and promotion of the human rights of those infected with HIV/AIDS”, more commonly known as Decree 27-2000. It resulted from an initiative taken by HIV and/or AIDS-affected people to organize themselves to fight for universal access to treatment and respect of their rights. SOS Children’s Villages considers it to be its responsibility to take part in this struggle and contribute to the fight against HIV/AIDS at the international, national and local level. The most important challenges in this respect are raising public awareness about HIV/AIDS and undertaking prevention work.

SOS Children’s Villages Guatemala sees itself as a protagonist in the fight against HIV/AIDS and cooperates with State and civil institutions to this end. SOS Children’s Villages’ primary concerns are to prevent HIV transmission and promote the rights of people affected by HIV/AIDS. As well as providing practical support in the SOS Children’s Village facilities,

SOS Children’s Villages has spoken about the issues on local radio and television stations and initiated activities in cooperation with the ACSLCS (Asociación coordinadora de sectores de lucha contra el SIDA), a federation of 30 non-governmental organizations that represents the population and their rights in terms of HIV/AIDS.

FACTS AND FIGURES ON HIV/AIDS IN GUATEMALA¹

HIV prevalence in adults is estimated at less than 1% (end of 2007). Around 59 000 people are living with HIV; 13 000 people need antiretroviral therapy (ART); every day 26 people become infected in Guatemala.

Guatemala has a very young population (50% under 18 years old); approximately 80% of people are living in poverty. The majority of those with AIDS are adolescents and young adults. There are two infected men for every infected woman, but there is concern about the gradual increase of HIV in women. There is no reliable data available on prevalence among indigenous groups and children. People who publicly acknowledge being infected with HIV encounter strong stigma and discrimination.

There are currently 7,800 people living with AIDS receiving free ARV treatment; this figure is expected to reach 10,000 by 2010. The sustainability of care is not guaranteed and antiretroviral drugs are still in short supply. HIV tests are not available nationwide. According to WHO, about 94% of HIV infections are attributed to sexual transmission.

The institutional response to HIV is well established in the capital, but weak in the rest of the country. A national law passed in 2000 (Decree 27-2000) declared HIV/AIDS and sexually transmitted diseases to be a problem of national urgency and provides for protection of human rights in the face of HIV/AIDS. Guidelines and standards have been developed for the clinical management of HIV infection. However, despite increased domestic and international funding, resources available are far below those needed to control the HIV epidemic in Guatemala.

¹ Source: UNAIDS (Guatemala country profile, July 2008)



THE “FAMILY SCHOOLS” OF SOS CHILDREN’S VILLAGES

Families that are cared for in the SOS Hermann Gmeiner Social Centre and the community centres attend “family schools” set up by SOS Children’s Villages Guatemala. 400 families, mostly women, have participated in workshops in the family schools since the programme began five years ago. The participants include not just mothers and fathers but also young people and other family members. The workshops are aimed at specific age groups, with adults and young people in separate groups. The emphasis is mainly on prevention and modes of transmission, with the primary focus being on preventing vertical transmission, i.e. transmission from an infected mother to her child. Topics such as HIV, AIDS, sexually transmitted diseases, sexual and reproductive health are largely unfamiliar in rural communities, in particular among the native population. Young women in particular know little about it and are shy of talking about it. Few parents talk to their children about HIV and AIDS - children are more likely to get hold of the relevant information through other channels. Therefore, the family schools invite specially trained educators and HIV-affected people, who tell their stories.

The workshops at the family schools use the “Educación Popular” approach, an adult education methodology in line with the “Education of Liberation” developed by Paulo Freire, in which learning and knowledge

The voices of those affected

SOS Children's Villages Guatemala is involved in the preparations for the Central American HIV/AIDS congress, CONCASIDA, which will take place in Costa Rica in 2010. The preparations are channelled through the National Committee of Guatemala in coordination with civil society organisations and the national AIDS programme. In the course of these preparations we had the opportunity to interview Alma León, the president of the Guatemalan National Alliance for Groups of People Living with HIV/AIDS (Alianza Nacional de Grupos de Personas que viven con VIH y Sida de Guatemala) and member of the "Comité Nacional CONCASIDA". Mrs de León is renowned at both national and the international level for her promotion of respect for the human rights of people with HIV/AIDS.

FORUM: How was the Guatemalan National Alliance for Groups of People Living with HIV/AIDS founded?

Alma de León: It was a result of the need to integrate and organise groups of people with HIV/AIDS. It aims to promote their active participation in political life. The National Alliance also integrates groups that work on the topic at national level. The systematic syndication of people living with HIV/AIDS is the most powerful weapon for combating this disease, making a difference and

ensuring respect for human rights. The most important people in this fight are those infected with or affected by AIDS.

FORUM: What would you consider the biggest successes with regard to HIV/AIDS?

Alma de León: There are many. We have a law on the fight against HIV/AIDS and the promotion, protection and respect of human rights, which was adopted by the Congress of the Republic in 2000. Since 2005 there has been a policy and a strategic national plan for the prevention, care and control of the sexual transmission of HIV/AIDS and a national committee – CONCASIDA. The national alliance has made a significant contribution to these achievements.

FORUM: Which are or were the greatest challenges?

Alma de León: First and foremost is universal access of people with HIV or AIDS to comprehensive treatment. At present they receive medication thanks to contributions from the Global Fund. The decentralisation of services continues to be another big challenge, which is still on the political agenda. Another major concern is increased financial resources for the national AIDS programme: so far, the programme has received only 40% of the resources it needs.

acquisition are based on the hands-on experiences of the individuals and the groups themselves. This builds a relationship of trust between the educators and the participants and allows doubts and uncertainties to be addressed and frequently overcome. Many participants ask for advice from the educators, the workshop leaders and the programme director.

Participants are also taught about the importance of the voluntary tests and encouraged to undergo a voluntary AIDS test, with parents bearing responsibility for having their children tested as well.

The workshops cover the issues of stigma and exclusion, which frequently stem from a lack of information about HIV/AIDS and in particular about modes of

transmission. The workshop also includes information of other kinds, such as the current Guatemalan law on the protection and promotion of human rights in the fight against HIV/AIDS, which requires the protection of and respect the human rights of people affected by HIV/AIDS, including the right to employment. An AIDS test is neither a requirement for a work contract nor can it be a ground for dismissal. The workshops held with the families in the family schools that are based on the Educación Popular are an example of “Best Practice”. They enable participants to share the knowledge and experiences of people infected with HIV and AIDS to become informed and to develop understanding and sympathy for those affected.

EXCHANGE WITH OTHERS

SOS Children’s Villages has also contributed to the education of children, young people and adults in the framework of partnerships with other organisations. These include two meetings in 2006 and 2007 on the subject of “HIV/AIDS-affected children”.

The first national meeting was given the motto “We, the children, also have an opinion” and was organised by the “Fundación Preventiva del Sida”, SOS Children’s Villages Guatemala and the “Red Nacional de personas que viven con el VIH y Sida”.

Sixty children aged 4 to 18 from various regions of the country participated in the meeting. The aim was to find out what children and young people knew and thought about HIV/AIDS in order to enable them to participate in the organisation of HIV/AIDS programmes and projects. The meeting also focused on an exchange of opinions and experiences about the way parents and carers deal with children infected or affected by HIV/AIDS.

The subject of the second national meeting was “Comprehensive protection of children and young people affected by HIV: reality from the point of view of the families involved”. The meeting comprised analysis, reflection and suggestions about the reality of the children and young people affected. There was also an emphasis on finding out which of the rights of children affected by HIV/AIDS were most violated and what kind of care these children needed. A total of 75 children and families participated in this meeting.



Both meetings were held in the training centre of SOS Children’s Villages Guatemala. UNICEF, Plan international, World Vision, Procuraduría de Derechos Humanos, and “Movimiento Social por los derechos de la niñez y adolescencia” also participated. As a result of this meeting, SOS Children’s Villages joined the ACSLCS in 2008. The organisations participate jointly in events and meetings and are working, amongst other things, on a contribution for the Central American HIV/AIDS congress, CONCASIDA, which will take place in Costa Rica in March 2010. ■

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LIVING A BETTER LIFE



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In February 2007 an SOS Family Strengthening Programme was launched in Temirtau, an industrial city of around 180,000 inhabitants in eastern Kazakhstan. The region is characterized by its high unemployment rate and extremely high level of AIDS- and drugs-related deaths. Quite logically, it was decided that families with adults and/or children who were infected with or are at risk of contracting HIV, as well as families with drug and alcohol problems should be the primary target group for the Family Strengthening Programme. School children who are supported by HIV-related preventive measures formed another target group.

As a first step 165 children from families in need received long-term support from a team of professionals, and parents had access to the free services of a lawyer, psychologist, and speech therapist. As a result, the living conditions and life skills (food, health, school progress, behavioural changes) of the families have improved, as have relations between the children and their parents. In addition, there has been a noticeable decrease in the use of psychotropic drugs and a greater awareness of issues related to safe behaviour.

Maria Vladimirovna S. and her children form one of the families supported by the Family Strengthening Programme. Maria, a 26 year-old single mother of two, is HIV-positive. She approached the project for help after she found herself in a crisis when her husband was sentenced to a prison term. At the point when she was accepted into the project, the family did not have any income of its own, and she had begun to drink. Because she did not have a residence permit, she was not entitled to accommodation or welfare benefits.

In the context of the Family Strengthening Programme, she received psychological support and parental skills training as well as legal advice. She was able to take part in leisure activities and sign her children up for recreational activities, including the SOS Playbus project. Other help included monthly food



parcels, clothing and vitamins for the children, as well as one-to-one family support from social workers.

As a result of the work carried out, the family obtained a residence permit, and with it, the right to social welfare benefits. The family's situation improved, as did Maria's own health. She gets on better with her children now, taking responsibility for their education, and she has stopped drinking.

NEEDS AND RESPONSES

Maria is a good example of how those affected by HIV/AIDS can benefit from the Family Strengthening Programme in Temirtau. The offered services are broadly in line with the needs assessment undertaken by the UN Development Programme in August 2005 and some of the proposed support measures for people living with HIV. They include:

- social protection, including material assistance
- help in looking for a job and ensuring job retention
- providing information about HIV and ARV therapies for people living with HIV/AIDS
- psychological support in relation to HIV

The aims of the SOS Family Strengthening Programme are to:

1. Decrease the risk of abandonment and improve living conditions for children and young people from

risk families, including families affected by HIV/AIDS.

2. Support the community in providing assistance to children and families who suffer from HIV/AIDS, have drugs and alcohol problems, and are living in a crisis situation.

Temirtau: Facts about the region

Temirtau is one of the poorest regions in Kazakhstan with the highest level of deaths caused by HIV/AIDS and drug abuse, not only in Kazakhstan but in the whole of the CIS. Many of the families that the SOS Family Strengthening Programme Temirtau works with are on low income or have no permanent income, have been to prison, suffer from drug or alcohol addiction, have problems with housing, live in conditions putting them at risk of tuberculosis infection or suffer from social stigma. This all places them at an increased risk of HIV infection and makes them outsiders in society. Some of the HIV-positive women are pregnant and some of the women are sex workers. Children from target groups do not attend nursery school and are often socially isolated. They don't have adequate opportunities to develop or suffer from violence and constraints.

At present, local community action cannot provide an effective response to this situation. Apart from the SOS Family Strengthening Programme there are no organisations working in the area of family strengthening, providing individual support for children from families at risk as well as to their parents. This individualized and holistic family approach complements the work of The Centre for the Prevention of and Fight against AIDS in Temirtau, which is the main national organization providing, amongst other things, psycho-social support for people who are HIV positive or have AIDS. This organization is supported by the local NGO "Shapagat", a public charitable foundation.



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CASE PLANNING AND MANAGEMENT

So how do people become beneficiaries of the Family Strengthening Programme? When a family applies to the project, the staff carry out an assessment of different aspects of the child's development as well as the family's situation, which includes a home visit. Based on this initial assessment, the team makes a decision on whether to admit the family if they fit the admission criteria.

The families are accepted according to the schedule, and sometimes there is a waiting list. Exceptions are made for families in an urgent situation. On admission to the project, the family signs a contract and a family development plan is worked out jointly. The situation of the family is monitored and regularly reviewed to assess progress towards the goals defined in the family development plan. For families affected with HIV/AIDS, the project members discuss the needs of the family with a representative from the AIDS Centre.

On average, the families participate in the project for 2.5 years. There is no formal follow-up for families who have left the project, but the staff ensure that families continue to take part in parent's clubs and group meetings.

SERVICES OFFERED BY SOS CHILDREN'S VILLAGES

In 2009, the project provided the following services for children and carers and access to other service providers was facilitated:

- Health support: the project pays for medication, vitamins and medical examinations according to needs. Families registered with the AIDS Centre have access to ARV therapy.
- Recreational support for children: after-school recreational activities (dance clubs, sports, etc), which are provided free of charge by local groups.

■ **Educational support:** children are supported by social workers and encouraged to learn through individual discussions. There are already indications of positive results. The staff evaluate progress twice a year with the help of the children's school reports. Recently, the project has started providing computer classes through its partner organization.

■ **Nutritional support/food parcels:** this is one of the main forms of support provided for families by the project as healthy and balanced nutrition is important during ARV therapy. In addition to the support provided by the project, there is a local state programme providing children from grades 1 to 4 with hot meals at school free of charge. For children above grade 4, hot meals are given according to individual needs (based on the family's situation).

■ **Psychological support:** Group activities and individual counselling is provided by the project's psychologist although the project premises are not really suitable unless there are separate rooms to allow for privacy. Group activities are organized in the local school.

■ **Parental skills training and information sessions** on children's rights are organized during parent's clubs and other meetings. Every quarter, the project organizes internal training on improving parent-child relationships. In addition, support is provided by the SOS Playbus. The project has developed useful educational handout materials for improving child-parent relations.

■ **Vocational training/employment assistance:** since 2009, the project has offered vocational training (i.e. cooking, computer skills) for carers through cooperation with a training provider. In terms of assistance in seeking employment, the project works with the State Employment Agency.

■ **Legal support:** this service is in high demand in the project: services are provided by the lawyer who works for the project. The project has developed educational handout material about legal rights of families.

In the future the project will also work more closely with the SOS Playbus, a mobile social centre for children that provides imaginative play materials and stops off at public parks and hospitals, orphanages and high-rise concrete apartment blocks. Activities such as drama, dancing, dressing up, face painting



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and various craft activities are designed to help children to achieve confidence in themselves and in others. The educational games teach the children about their rights, HIV/AIDS, caring for the environment and other topics. During the events the Playbus team shows parents and teachers new teaching methods and encourages them to develop new ideas.

The participation of the community and partnerships is essential to keep the project firmly rooted in the region. Several partners were involved in developing the programme, including the local city council, the Centre for the Prevention of and Fight against AIDS of Temirtau, a rehabilitation service for children and teenagers in problematic situations, as well as other local NGOs.

One of the programme's aims is to support independence within the community and empower community members to become self-reliant in caring for vulnerable children and their families. Accordingly, the local community is supported by the new infrastructure created by the SOS Family Strengthening Programme. The project has not yet focused enough on targeted awareness raising activities and involving community representatives in implementing the project. Once every six months SOS holds round tables to exchange information with other organizations about the situation of children and the solutions provided. The project also uses volunteers. The mentoring support given to two FSP beneficiary mothers by two SOS mothers is an example of the good practice that is emerging. The project has established a Project Committee, which



in addition to the family strengthening staff consists of a doctor, a social worker and a cashier from SOS Children's Village Temirtau. However, the primary role of this Committee is to have a multi-disciplinary approach in assessing the individual needs of the respective families.

Although the project has reliable partners, it lacks strategic alliances and the assurance of complimentary service delivery. In the future, established partnership networks need to be extended.

MONITORING AND EVALUATION

The programme is monitored with partners. Self-evaluation is carried out annually, based on the following success indicators:

- Number of children from disadvantaged families and members of their families that are supported on a long term basis by a professional team.
- The living conditions and life skills of children, including those who are HIV positive, will be improved (stable health, good nutrition, success at school, spare time activity, positive behavioural changes, communication with peers, parents/guardians and other family members).
- Parents with a life-threatening disease such as HIV/AIDS have access to support services and are able to care for their children.
- The parental skills in families of the primary beneficiaries will be supported.

- Possible decrease of drug use among young people and greater knowledge about HIV/AIDS.

Existing system of support for children and families at risk in the city in cooperation with administration and NGOs.

- Families have the financial means and practical skills to care for their children.

THE NEXT STEPS

By 2010 staff would like to increase the number of beneficiaries to 250-300 and extend the services by offering educational services for children, health support services for families, as well as services leading to financial independence.

Different assessments have shown that long term planning must be improved as family situations are sometimes tackled through an ad hoc approach, without properly analysing the risk factors and identifying the self-reliance indicators for an individual family. Yet a good basis has been put in place for the next steps: the project team has established trusting relationships with the families, and the families receive emotional support from the project staff. It's a solid rock on which we can build. ■

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LEARNING TOGETHER AND FROM EACH OTHER: THE “JOINT LEARNING INITIATIVE ON CHILDREN AND HIV/AIDS”

The “Joint Learning Initiative on Children and HIV/AIDS (JLICA)” is an alliance of researchers, implementers, activists and people living with HIV/AIDS. The initiative strives to improve help given to children affected by HIV/AIDS across the globe. The organisation is based on four pillars, i.e. four interdisciplinary “learning groups” which have undertaken scientific work in this field, supported innovative solutions and promoted exchange between disciplines and the various partners. Particular emphasis was placed on ensuring balance with regard to the participants’ geographic origins, gender and disciplines.

The achievements of the four learning groups are presented in detail on the comprehensive website <http://www.jlica.org/>. An overall report published in 2009 summarises the more than 50 systematic reviews and other research results and makes recommendations about how to work with children affected by HIV/AIDS. The result is an evidence-based guideline that describes how to respond to the situation of children affected while emphasising the importance of putting the children and their families at the centre of our efforts. The target readership for the report is politicians and other decision-makers in countries particularly affected by HIV/AIDS, but it also addresses sponsors, NGOs and other members of civil society.

According to JLICA, the HIV/AIDS pandemic has reached a point at which we need to revise or expand our thinking: infection rates are stabilizing and in some regions are even declining. At the same time it is obvious that, realistically, the pandemic cannot be overcome. HIV and AIDS will remain part of people’s

lives, in particular for those living in sub-Saharan regions, and so will continue to test the resilience of families, communities and nations.

Whilst the report acknowledges the achievements made so far as well as what has been learned from the past, it also calls for more extensive support, in particular to protect and support children. It says that universal access to medical care must go hand in hand with social security. This integrated approach is needed to create conditions that enable people affected by HIV/AIDS to benefit from prevention, treatment, care and support.

According to JLICA, these measures can, in a short time, bring about substantial improvement in health and living standards and move away from the acute emergency aid that has tended to be the mainstay of our approach until now.

The strategy described in the report strengthens families affected by HIV/AIDS and goes beyond singling out individual cases, which has the consequence of stigmatizing them to a certain extent. JLICA is convinced that it is paving the way for a new model of health and cooperative development work that has the potential to be able to repair the damage caused by the interdependence of illness, poverty, inequality and food shortages. ■

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WE FURTHER RECOMMEND...

Yes, they can! Children researching their lives

Fiedler, Julia / Posch, Christian (2009), Baltmansweiler, Schneider Verlag Hohengehren GmbH, € 19,80

Available in English only. Please order from: researchingchildren@sos-kd.org or www.paedagogik.de

“When Knowledge Sparks a Flame.

Knowledge communication in the international non-profit organisation SOS Children’s Villages”

Lechner-Kreidl, C. / Hilweg, W. / Nguyen-Feichtner, M. / Reinhardt, R. (2007), Peter-Lang-Verlag, Vienna, € 24.80

Available in German, English and Spanish from academy@sos-kd.org or in bookshops.

Fremd und doch zu Hause. Qualitätsentwicklung in der Fremdunterbringung (A stranger and yet at home. Quality development in out-of-home care)

Hilweg, W. / Posch, C. (2008), Schneider Verlag Hohengehren, € 18

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