

# THE IMPACT OF HIV/AIDS ON CHILDREN

## EDITORIAL

According to the State of the World's Children Report (2006) some 15 million children have already lost one or more parents to the HIV/AIDS epidemic. Of those orphaned by AIDS, 12.1 million, or more than 80%, are in sub-Saharan Africa but the number is growing elsewhere as well. The Anglican UN office in Geneva has been working on a study on the Anglican Response to HIV/AIDS in Africa (see overleaf). It has stories of practical action and of different denominations and faith groups working together. And we need such encouragement and concerted effort in the face of the devastating effect of the pandemic, not only on the lives of

the orphans, but on families and communities worldwide. As the articles which follow make clear, in some parts of the Anglican Communion the statistics are known and horrifying; in others, the known numbers are small but the problems of combating ignorance and stigma are huge. This newsletter focuses on the impact on children. The picture above, drawn by a child, shows only too clearly the impact of HIV/AIDS – a young life is turned upside down. This terror comes to those whose parents are infected and who have to cope with stigma, illness and death; to the children who have to become adults to look after their siblings; and to the children themselves infected with the virus, whether through mother-to-baby

transmission or through sexual or drug abuse. Jesus, incarnate as a child, called on his followers to care for children. We, who celebrated His birth at Christmas, must give higher priority to this call.

IAFN International Anglican Family Network

### **IAFN HAS MOVED** **Change of postal address**

C/o Anglican Communion Office,  
St Andrew's House,  
16 Tavistock Crescent,  
Westbourne Park,  
London W11 1AP, ENGLAND  
email: [mail@iafn.net](mailto:mail@iafn.net)  
Tel: +44 (0)7948 332697

# WORKING TOGETHER – REPORT OF THE ANGLICAN RESPONSE TO HIV/AIDS IN AFRICA

In many ways I'm not an expert on AIDS. This despite having been busy over the past six months overseeing a study on the Anglican response to HIV and AIDS to put before the World Health Organisation and UNAIDS and to encourage us Anglicans in working together on the challenge.

The people who are the experts are those whom we have come across: children, women and men who find themselves living with HIV or affected by AIDS and who do so with great dignity and courage. They are experts on the impact that AIDS has on every aspect of life; but at the same time on what the response can be. Both are found in stories. Always those stories are humbling and profound. Inevitably the impact on children touches us most deeply, as it should.

Hard to tell the whole Anglican story in our study, so we focused in on a few small corners of Africa. From Tanzania comes the story of St Albans parish near Korogwe where 70 children aged from three to 15 years – all of them having lost one or both parents to AIDS – are cared for and supported in their education and health needs by parishioners. They are from different denominations and religions (18 are Muslims). There is no agency or donor. The parishioners themselves find the means despite the fact that their own resources are meagre.

In Kenya, Maseno Anglican Hospital provides a comprehensive level of treatment offered by doctors, clinical

## CHURCH WITNESS

officers, nurses, pharmacists and counsellors. There is also a children's club offering psycho-social support. Children can express themselves and get over their anger. Near Kakamega, the 'Jikaze' support group was a vital lifeline to 40-year-old Fanhae Emitunga: "The greatest enemy is self stigma" she says, "The church helped me overcome it." Now her condition is stable and she is able to look after her four children.

The good news is that Anglicans are responding here and, as this newsletter shows, in many other countries and continents. This flowering of initiatives and creative responses is all the more effective because it draws its energy from the grassroots, from the faith and committed application of Christian principles by individuals and church

communities around the world.

We worship a God incarnate, who we believe is among us and therefore to be found in the midst of the world's places of struggle – places where AIDS has decidedly not gone away; where, in fact, it is more than ever at the top of the agenda. One senses that the more we can work together in our response, the more we will discover a unity of purpose and identity amidst our diversity, and the more we will live out a Gospel of incarnation which addresses the truly important issues of our day.

## SOUTH AFRICA

### RAPHAEL CENTRE

When I first met Pamela she was five years old and too weak to walk. She was carried everywhere on her mother Nonkhundla's back. Nonkhundla found out that both she and Pamela were HIV infected, after months of suffering and recurrent illness. She spent all of the family's meagre income at the Sangoma (witch doctor) undergoing agonising rituals for the banishment of evil spirits. Eventually, almost as a last resort, she visited the Raphael Centre for people living with HIV/AIDS in Grahamstown. Nonkhundla's greatest fear was that she would die before her child and she had heard that we sometimes look after sick children.

At that time, no anti-retroviral (ARV) treatment was available to poor people in South Africa. Our support of Pamela and Nonkhundla involved ensuring that they

obtained life-skills and good nutrition. This was beneficial because their health improved and they suffered from fewer opportunistic infections. However, after the Government had been compelled by court cases to make treatment available to the poor, we were able to ensure that Nonkhundla became one of the first in our region to be treated with ARVs. This was immediately successful and she now has an undetectable viral load. We were then able to argue that Pamela also needed treatment. Subsequently, Pamela became one of the first children in our community to receive paediatric ARVs. We also have a programme geared toward preventing children like Pamela from ever becoming infected. Our prevention of mother-to-child transmission targets pregnant women and encourages voluntary counselling and testing. If pregnant women are aware of

their HIV status, treatment can be provided. We also educate women about ways of minimising transmission of the virus to their baby.

The Raphael Centre supports 160 AIDS-affected children like Pamela. There is no orphanage in our community and we support children in the homes of caregivers. Children living in AIDS-affected homes have a higher rate of absenteeism than their peers, and are more likely to leave school altogether. This can be attributed to the stigma still surrounding AIDS and those associated with it, and the financial burden placed on children with parents unable to work. At the Centre we try to counter this by paying school fees and providing school uniforms and emergency food parcels. We believe that encouraging orphans and vulnerable children to stay in school for as long as possible increases their life

chances. We have had remarkable success. In the past six years, only two out of several hundred children supported by us have dropped out of school.

Pamela, the child who was too weak to walk, is now thriving in school. She is bright, agile and, according to her teacher, capable of whatever she sets her heart on. The last time I spoke with the nine-year-old, she was not quite sure of her future career plans but was dreaming of becoming either a rock star or a famous fashion model.



### ST ANNE'S HOMES

The impact of HIV/AIDS on the South African child is enormous. Of the 1.5 million orphans in South Africa (maternal orphans under the age of 18) about two thirds were orphaned due to AIDS, with 300,000 becoming orphans in 2006 alone, according to the Actuarial Society of South Africa report in 2006.

Orphaned children experience enormous pressure as they often have to assume adult roles in treatment, care and support. Surviving siblings suffer stigma and discrimination in their communities. They are also much more exposed to violence, abuse and exploitation and drop out of school for a variety of reasons. In addition, orphaned children experience the loss of caregivers and lack of access to essential services such as education and health care.

While residential care is widely perceived as the last resort for addressing children's care needs, orphanages are mushrooming

across sub-Saharan Africa. Major international agencies concerned with the needs and rights of children, such as UNICEF, advocate that residential care must only be a temporary "last resort" for children without parental care.

These agencies and literature repeatedly reiterate negative impacts on children resulting from residential care: e.g. it marginalises children from society and results in stigma; it fails to transfer critical life skills to children resulting in their being inadequately prepared to cope with life when they leave care; it frequently fails to respond to children's individual needs – characteristically prioritising the needs of the institution.<sup>1</sup>

St Anne's Homes, a shelter in Cape Town which cares for and empowers pregnant, abused and homeless women and their children, has been overwhelmed by the scourge of HIV/AIDS. We believe that the sacred bond between mother and child must be preserved at all costs. In the past few years, we have received a number of referrals suggesting the mother and child be separated because of their HIV status. We constantly have to stress that HIV is not a good enough reason to separate a child from its mother, especially when there is sickness. At the same time, we have been struggling, due to a lack of capacity, to meet the needs of temporarily ill HIV-infected mothers and children. In one such case, where the mother became so sick that we could not keep her in our care, we were forced to refer her to an organisation that runs an adult hospice and orphanage. Although the child was not with the mother, at least they were in the same organisation. St Anne's Homes have since had to expand their own HIV/AIDS programme.

South Africa has developed various policies addressing the impact of the epidemic on children. Interventions targeting vulnerable children focus on the provision of Home- and Community-based Care Services and the establishment of community Child-Care Forums to identify and support children. The Orphans and Vulnerable Children's Policy Framework, in addition, recommends the provision of formal foster-care placements for orphans in an attempt to reintegrate orphaned children back into families.

It was due to the strength of civil society and HIV/AIDS activists that the South African Government was not able to downplay the enormity of the epidemic. Instead, under the leadership of the Deputy President, the Government's response improved and the Government, through the President's office, has called on religious communities to help in addressing key social problems, including HIV/AIDS.

The Anglican Church in South Africa, under the leadership of Archbishop Njongonkulu Ndungane, is playing a central role in addressing the issue both within the Communion and on an interfaith level. For more information on the church's programmes visit [www.fikelela.org.za](http://www.fikelela.org.za) and for more information on shelters for mothers and children visit [www.stanneshomes.org.za](http://www.stanneshomes.org.za)

*'Home Truths: The phenomenon of residential care for children in a time of AIDS, 2007:9*



## ZIMBABWE – MANICALAND DIOCESE

During my visit to Zimbabwe in June 2007, I was involved in charity work with the Mothers' Union in Manicaland, travelling around some of the rural villages and communities providing assistance to orphans and others in desperate need. Orphans and vulnerable children in Zimbabwe experience much struggle and hardship in trying to cope with the daily pressures in a nation greatly entangled in economic and political problems and where aid is scarce. The number of children affected by or living with HIV/AIDS has been rising in Zimbabwe. Manicaland, one of the country's ten provinces, has approximately 200,000 orphaned children.

I was fortunate enough to be able to discuss some difficulties with an orphan named Chipu who was aged about nine. She shared with me some of the tough experiences that she faced when she lost both her parents to HIV-related illnesses. Chipu lost her father first and was left alone to bear the burden of caring for her ailing mother for six months before she too died. She could not have managed at all without the help of her widowed neighbour who sometimes assisted when she was away in school by looking after her sick mother and her other two siblings, one aged five and the other two. Chipu looked sickly and weak and very miserable and now lives with eleven children, all of whom have lost their parents. I wanted the elderly woman who now looks after her to take her to hospital but I do not think she did because it is quite a distance without reliable transport.

There are many others like Chipu, who are forced to look after themselves and to head households. Others have widowed grandmothers to look after them, but they too have no resources and need help themselves. The orphans are very vulnerable as they could be subjected to all kinds of serious abuses such as child labour and sexual exploitation.

Where lives of orphans in their village or community have been found to be unsustainable, they have been placed in orphanages. Many of these depend on church funds and donations and with the economic problems facing Zimbabwe at the moment, the Diocese cannot cope with the repairs and they are terrible. I

saw leaking roofs, broken-down toilets and broken floors. One orphanage, attached to a hospital, used to have a garden which was self-sufficient, but now the borehole and the supplying well are dry and the leaking pipes need replacement. Much effort is being made throughout the country to limit placements in orphanages and find better ways of having children remain in their communities where they might be able to experience more of family life.

The Mothers' Union makes a great effort to relieve hardships and make the orphans' lives a bit more bearable by providing them with food, clothing, blankets, books and toys as well as access to medical and health resources. They also give financial assistance so the children can attend school. Housing and accommodation assistance are provided. During the visit, the Mothers' Union members handed out blankets to many orphans (sadly there were not enough for all those who had been identified).

To raise money for these projects, the Mothers' Union engages in activities such as selling and trading household commodities and vegetable marketing. Members of the community assist in the building and construction of schools, some by providing bricks from their own resources and others by moulding the bricks on site.

Psychological support is given especially to AIDS/HIV orphaned children so they are able to cope with saddening losses of

their families and loved ones by providing counselling services, helping them create happy memory family books, and providing relaxation and therapy centres for them to adjust to their circumstances. The Mothers' Union also tries to identify parents who wish to foster, adopt, or provide holidays, overnight or long weekend breaks for the children.

Mothers' Union members also visit the orphans to befriend them and promote life skills. They may assist the youth with training for such projects as how to form and run savings and lending groups, and farming activities such as chicken-rearing and crop-growing to sustain themselves in the future.

Provision of support to vulnerable, disadvantaged and HIV/AIDS orphans is an on-going exercise for the Mothers' Union in Manicaland and we are looking forward to expanding our work to cover more communities and villages. The Mothers' Union meets regularly with leaders of the church, village elders and members of the community to discuss how everyone can best contribute towards the successful building of a better society. The Mothers' Union is grateful for all those who contribute wholeheartedly for the betterment of these suffering children through the generous donation of time, finance and other help.

## INDIA

risk target groups – the sex workers, truckers and drug users – and only 20% of AIDS funding goes to caring for children and families living with HIV. One out of every three people infected with HIV is a woman, and 80% of these women are housewives. That has a direct link to children.

Children whose parents have HIV/AIDS also suffer: many are forced to withdraw from school to care for them, are forced to work to replace their parents' income, or are orphaned. Although the Government has not conducted studies to assess the number of children affected by AIDS, some experts calculate that nearly two million children in India have lost their parents to AIDS: this is the largest number of AIDS orphans of any country and is expected to double within five years. India is now home to the largest HIV-positive population in the world with 5.7 million infected. In May 2006, the Joint United Nations Programme on HIV/AIDS (UNAIDS) reported that India had overtaken South Africa to become the first non-African country to report such alarming numbers. The disease is silently spreading and reaching critical proportions. The sheer size of India's population – more than one billion – makes the probability of a widespread AIDS pandemic frightening. HIV/AIDS worldwide carries stigma and taboo. India is no exception and the culture of silence is predominant. Protection means providing empowering education. In India, the conspiracy of silence continues to subdue the sex education and HIV/AIDS interventions in schools. In a country where 70 out of 100 children already drop out of school by secondary level, children affected or infected by HIV/AIDS face significant barriers to attending school. These include discrimination by teachers who separate them from other students or deny them admission entirely. HIV-affected children often have frequent absences due to opportunistic infections that schools do not tolerate. The children fear revealing that they are HIV-positive in order to ask for special measures; and the loss of a family wage earner leaves them unable to pay school fees. They are also expelled from schools if any member of the family is found to be HIV-positive.

Becoming orphaned is not the only way children are affected by this epidemic. There is also a devastating impact on their emotional and psychological wellbeing. They are missing their entire childhood as they go immediately into adulthood at a very young age. They are the most common caregivers for sick parents and eventually watch those parents die, after which they all too often must step into adult roles themselves, becoming the guardians of younger siblings or working to support their

remaining family. They may be denied their property and inheritance rights, often face discrimination from the community, and must deal with fears for their own health. Alarming new evidence by UNAIDS found that orphans and vulnerable children have a higher risk of exposure to HIV than non-affected children.

Girls are especially vulnerable. They are not only more likely to be removed from school to care for sick family members but are often the last to receive medical care. Loss of family income quite often pushes them into the sex trade and inability to control safe sex, even within marriage, puts them at a disadvantage. Less access to education, sexual abuse and child marriage, all place girls at higher risk of becoming infected. Many families marry daughters off at increasingly young ages so the girls will have someone to care for them after their parents die. Parents are also afraid of HIV rendering them unmarriageable. This has the added effect of creating a lot of very young widows.

Rupa (name changed) was only 13 when she was married. Widowed when she was 14, now at the age of 15 she is living with HIV. She was blamed for the death of her husband. Her siblings were thrown out of school because of her HIV status. Her family was discriminated against in the community. She has no place at her parent's home or in her husband's house. Rupa never received any education and has no skills for employment. Still a child, she lives on the streets, begging for food. She is sexually abused by the older men in the streets, including the police. Sometimes she earns a few rupees from them. She is expecting her baby soon. She does not even know that her child could be prevented from contracting the virus. The question is, even if she knows, how can she prevent it? When she went to the nearby hospital, she was asked to leave because she is a "bad girl". Rupa has no place to go, and yet is soon bringing another life into this world. Who is responsible to care for both these children and the millions like her in the country? It is time for everyone to wake up. The Government, the civil society in India – and the Church – need to address the concerns of children and impacts of AIDS on them, by protecting them from abuse and violations of their rights. Today is the time to nurture the future of the country. Quoting Gabriel Mistral "...To them we cannot answer tomorrow, their name is Today."

India has the largest child population in the world, with more than a third of its population below the age of 18. They are seen everywhere: the railway and bus stations; begging or vending at traffic signals; or homeless and lying on the pavements. They can be seen in villages, in the fields, in orphanages, even in brothels. They are virtually everywhere, yet are invisible, being virtually unnoticed by the world. They are the missing face of India!

Children are a vulnerable group to HIV/AIDS, whether they are infected, affected or at risk of contracting the virus. Children get infected by several means. Mother-to-child transmission is the most common source of infection in children at a rate of 30,000 per year. However, transmission is through sexual exploitation for the most vulnerable children and those at the margins, such as street children, child sex workers, sexually abused children, children of sex workers, children from lower castes and Dalits (so-called untouchables) and through blood transfusions; and unsterilised syringes, including injection drug use. While 25 million children in India are parentless, the number of sexually abused children in India is the world's largest, with a child below 16 raped every two and a half hours, a child below ten every 13th hour, at least one in every ten children has, at some time, been sexually abused according to a new government report. Also according to official statistics, in India hundreds of thousands of children are living with HIV/AIDS. However, government programmes and policies and interventions among the NGOs are least for HIV-positive children and for those orphaned. The Indian response to HIV/AIDS has focused primarily on high-

## BANGLADESH

Bangladesh is lucky. While the HIV virus was first found in the country in 1989, it still has a comparatively low rate of HIV/AIDS. According to government statistics in 2006, only 874 people from a population of 150 million have tested positive for HIV. However, this is likely to underestimate the true scale of the problem, and many people point to the fact that Bangladesh is a high-risk country with an increasing infection rate. The two main factors allowing HIV transmission in Bangladesh are unsafe sex practice in a growing sex industry and returning migrant workers who, having acquired the virus when working abroad, infect their wives when they return home.

It is within this context that the Church of Bangladesh Social Development Programme (CBSDP) has carried out its HIV/AIDS awareness and prevention activities since 2003. People are made aware of HIV transmission, prevention and treatment through community discussions, video shows and drama presentations, while brightly coloured billboards and posters help keep the topic in the public's mind. CBSDP also arranges workshops for groups of people particularly vulnerable to HIV infection, including bus and truck drivers, rickshaw pullers, day labourers and people of transgender (hijra). Special attention is also given to children and youth, with some teenagers given special training on how to raise awareness among their peers. Visits are also made to schools, supporting the teachers in using the HIV/AIDS material that has recently been included in government text books. The hope is that no-one can say they are ignorant of the risks of HIV.

But CBSDP acting alone will not be enough to change people's attitudes. Therefore, to increase understanding and help reduce discrimination of HIV/AIDS within the wider community, CBSDP

arranges seminars with community leaders (Imams, priests, local political leaders) and government staff to enthruse them to actively raise awareness of HIV and how to prevent its transmission. This is complemented by other work with adolescents and adults to promote women's rights and raise their status in society, which will make it easier for women to have more control over their sexual health.

All of this is having an impact. People, especially youth, are more willing to talk about HIV/AIDS, and many are passing on the message to family and friends. Attitudes are changing. For example, when people attend the barber, they are now more willing to buy a new blade than use a previously used one as before. Some Imams give speeches in Mosque during 'Jummabar' (mosque weekly service), inspiring people to follow the rules of religion to prevent HIV transmission. However, cultural attitudes to sexual health are deeply ingrained, and will take a lot longer to change. Ironically, the fact that the HIV rate is low and very few people know an AIDS patient, prevents many from appreciating the urgency needed to avert the possible sudden steep increase in HIV infection.

People with HIV in Bangladesh still face stigma and discrimination. Many people think that HIV and AIDS is a punishment that they deserve. Whole families suffer, becoming stigmatised from society and can be refused food from shops. Because of this stigma, most HIV-positive people do not want to tell of their infection. CBSDP has links with other NGOs that work with HIV-positive people, providing treatment and support for them. While the numbers are not huge (one organisation has 455 registered HIV-positive members including 134 female, 295 male, 24 children and two transgender – most of them migrant

workers) their work is important. They try to ensure as normal a life as possible for the sufferers, supporting them to live at home with their family and providing monthly health checks and medical treatment. Some organisations also have a special focus on children, supporting AIDS orphans by providing fees to enable them to continue their schooling, negotiating with village leaders and others should there be any problems, and providing nutrition support to the children and women. Without this support, these orphans would probably leave school and face a life of begging.

It is our prayer that all organisations can continue to work together to prevent the ravages of HIV/AIDS spreading throughout Bangladesh.

## ARGENTINA

The Siwok Foundation was set up to help preserve and promote the cultural, artistic and social values of the indigenous peoples of Northern Argentina. One of its concerns is the health of these people who inhabit the great flat scrub forest area known as the Chaco.

The largest group is the Wichi and one innovative way of drawing their attention to health issues is the annual ten-mile long Wichi Marathon. First held in 2003, this is a major social event with a serious message. Every year the marathon has a special theme, focusing on one of the

many health hazards. In 2006, the theme was HIV/AIDS (SIDA in Spanish) and participants wore a T-shirt bearing the question in their native language: Hä lehanej tä SIDA? (Do you know that AIDS exists?) Adults and children alike take part and there are prizes for different age ranges. The 2006 marathon was a fun way of highlighting a new and very dangerous threat to the lives of these people.

## TRINIDAD AND TOBAGO

Jonniebelle is a well-known figure in the beautiful Caribbean islands of Trinidad and Tobago. Her wedding three years ago was covered in all of the major newspapers. Her fame stems from her courage in telling her story of living with HIV, which is still a taboo subject in much of the country. Not many associate the Caribbean with HIV/AIDS but Jonniebelle's story illustrates the impact of HIV on the lives of children throughout these islands.

At the age of nine, Jonniebelle had her first sexual encounter. She was raped by her elder brother, the same one who introduced her to a church that he was attending. At the age of 11, her brother raped her again. Jonniebelle, who had been such an outgoing girl, became a prisoner of her emotions. She was transformed into a withdrawn, angry individual with low self-esteem. Her school work suffered and she finished school without a proper education.

Jonniebelle continued to attend church, going through the motions. At 17, she met a young man, an evangelist, and two years later they were married. They had five children but the effects of being raped as a child affected the marriage

relationship. Her husband became openly unfaithful to her and she was physically abusive to him. Her marriage of ten years ended in divorce. To ease her pain, she turned to marijuana, alcohol, cigarettes and promiscuity.

In 1991, she began to wonder if she had cancer. She was losing weight, had sores on her body, dizziness, fevers and swollen glands. Friends told her that she should be careful about one of the men with whom she had been having an affair. As her condition worsened, she decided to have a medical check-up. After various tests she discovered that she was HIV-positive. Jonniebelle's world crumbled underneath her. She was filled with rage and anger.

Incest, abuse and family breakdown are rife in these islands and the effects echo down the years. Many voices have begun to speak out about HIV/AIDS in Trinidad today. Jonniebelle asked God for a second chance and has been given the opportunity to share her experiences with many churches throughout Trinidad and Tobago.

Others have been concerned to provide programmes for education. Within the last six years, a programme developed at the University of Illinois in Chicago and

adapted for Trinidad and Tobago with the Family Planning Association (Trinidad and Tobago), has been instituted both in schools and churches. CHAMP (Collaborative HIV/AIDS Management Programme for Families) works with parents and teens aged 11 to 14 together, to strengthen family life, educate about HIV/AIDS and encourage teens to make wise choices. Lisa and her daughter Ishara attended a pilot course at All Saints Church, Port of Spain. Lisa works for the Trinidad Guardian and in her (patois) column she spoke of the benefits of the course:

Of course, it have alternatives to quarrelling. Me and Miss Thing start taking a workshop the other day. When you there struggling with your child, you does tend to feel you is the only one going through whatever it is. You feel you is the only mother who does get answer back, or can't get the children to bathe, or who child does come home smelling like cigarette and you don't know what to do.

It interesting to go to it because, as you must realise by now, I have a little problem with my temper. The last time in the class they ask parents what does make them trip off, I tell them my wares washing story, blushing red red fus I shame. But when I look around, everybody laughing – not at me, but with me. Is because everybody there, man and woman, rich and poor, does go through thing like that with their children once the children reach a certain age.

Two things I realising from this workshop. One is that I never miss a parents' support group until I had one; and two is that it good to have more information and a different perspective on how to be a better parent.

In a country where more than 2% of the population is living with HIV and where stigma and discrimination are still rife, these are small but crucial steps to protecting our children and ensuring a healthy future for our communities.

## GUYANA

HIV/AIDS was first identified in Guyana in 1987; in 1988 five women were among the 34 new cases. Statistics now show that women are 39% of all cases reported and 600 infants were infected with HIV during pregnancy, labour, delivery and breast feeding.

Approaches to prevent HIV infection in

infants and young children are: primary prevention – preventing unwanted pregnancies and HIV transmission from women to their infants; and provision of care and support to HIV-infected women, their children and families. In Guyana, prevention of mother-to-child

transmission is an integral part of all antenatal clinics.

The impact of this disease on families in Guyana is overwhelming. The sad fact is that despite the advertisements promoting safe sex and encouraging young people to abstain until marriage and the distribution of free

condoms, some of the males believe they cannot contract the disease. A large percentage of these men are married and indulging in extra-marital relationships. This reckless behaviour puts the unsuspecting wife at risk and when she becomes pregnant the child is also at risk. If the couple already have children and, as is the custom, the woman leaves it to the last moment to attend a clinic or have the baby at home, there may not be the opportunity for them to be counselled and possibly tested for HIV. If the parents do carry the virus and become too ill to work or die, there is no one to care for the remaining child or children. In some cases a grandmother or even an older sibling may have no choice but to take on the responsibility.

Due to the fact that this disease generally

affects the poorer class and Guyana has no Social Security to assist persons in need, the carer has to devise ways of survival. This often leads to children begging on the streets, prostitution, and sexual abuse, which in turn can lead to the further spread of the disease.

These children are not a part of the school system, leading to illiteracy, a scourge in the past but more recently almost non-existent in Guyana. While the number of vulnerable children is unknown, in 2002 the estimated number under 15 who had lost one or both parents to AIDS was 4,200.

The Mothers' Union continues to work actively in various ways to assist: we are involved in school feeding programmes, literacy classes for youths ages 14-30, HIV-awareness talks and workshops to groups in

churches, schools and clubs, and the distribution of hampers – especially to children who are vulnerable.

Recently Mothers' Union members, including myself, spent one week in the hinterland area educating and training a group of indigenous people of Guyana on HIV/AIDS, and also training 12 of them to train others in the future. This is one way of doing God's work in his beautiful garden and putting our faith into action.



## PAPUA NEW GUINEA

Papua New Guinea, with an estimated population of almost 5.9 million people, is the most populous nation in the South Pacific region (UNICEF 2005). It is a young population with 40% under 15 years of age.

According to the Human Poverty Index for 2006, 40.5% of Papua New Guineans live on less than a dollar a day and according to AusAID estimates, HIV rates are growing at about 25% per year. Within 20 years, 40% of the adult population could be living with HIV and AIDS.

It is estimated that there are now 10,946 children and young people infected by HIV, and 1,543 children aged two and under are living with HIV. The main mode of infection here is at birth. For those aged between two and nine, the estimated number of children infected with HIV is 3,152. It is difficult to state the main cause of infection in the age group due to the fact that ages might not have

been reported correctly. Is it possible that there is a high rate of sexual abuse – we do not know. From 10-14 years, there are 698 estimated children living with HIV. In this age range the main mode of infection is through sexual abuse, sex work, sexual behaviour and blood transfusion. This is also the main mode of transmission for those between the ages of 15-19 years, with 5,553 estimated children living with HIV.

The impact of the HIV/AIDS pandemic has affected all aspects of PNG society both in urban and rural settings. It is estimated that there are 138,108 children living in AIDS-affected families and a total of 620,585 children are at risk of infection.<sup>1</sup>

Some of the problems facing children affected by HIV/AIDS are:

- They are more likely to face stigma and discrimination. A mother living with HIV told me that when her

son mentioned in school that his mother and father were living with HIV, the attitudes of the son's classmates changed towards him. The teacher had to intervene by giving the class HIV/AIDS awareness lessons. Children living with HIV are more likely to be excluded from school because students and even teachers are afraid of being infected.

- They can be traumatised when they care for their ill parents. A young boy cared for his dying mother until she passed away. He was then cared for by relatives but they more or less ignored him and he had to fend for himself. He subsequently found out he was HIV-positive. By the time help was available for him, the infection had progressed to full blown AIDS. It was too late and he died. Children are traumatised when they are orphaned or separated from family and may be passed on from relative to relative. Because of abuse, some of the children end up living rough on the streets.
- They are sometimes isolated. Other parents might tell their children not to play with a child they know or assume to be living with HIV. This is partly as a result of fear for their children being infected. Children living with HIV/AIDS are forced to accept their situation and survive as best as they can.
- They are more likely to live in

<sup>1</sup>UNICEF: *Master Plan of Operation 2003-2007, Programme of Cooperation between Government of Papua New Guinea and UNICEF (2006) Families and Children Affected by HIV/AIDS and Other Vulnerable Children in Papua New Guinea*

families where resources are limited. This is because resources that would have been used for school fees, good food and generally maintaining a standard of living, would go towards medication, transport to a clinic and medical bills. Parents who are working might also lose pay as a result of being sick. A lot of organisations do not have an HIV/AIDS policy.

- They are more likely to also take up adult responsibilities which means that they might not be able to attend school. Some children might have to go out and work to augment their family's income. Due to lack of available work, sex work might be the option that is available.

Unlike in parts of Africa, we have not yet seen a significant increase in child-headed families. This is mainly due to the tradition and culture in Papua New Guinea whereby relatives and family members are usually available to foster or informally adopt children. However, the level of care and support within the families that the children receive might be inadequate and, as stated earlier, the children are sometimes discriminated against and abused. Unless the HIV pandemic is adequately addressed, as

more parents die, the relatives might not be able to absorb the children left behind into their own families.

### Intervention Programmes

The Anglican Church runs a number of intervention programmes most especially in remote parts of Papua New Guinea. These are Counselling training and training in Home-based Care. The majority of the people in Papua New Guinea live in rural areas. Access to medical care is often some days' walk away. Trained home-based carers are now able to provide palliative care in their communities.

An important way of reaching younger members of the villages is through Peer Education Training. This is a two-week course where people are given HIV/AIDS training to become volunteer Peer Educators. The participants then go back to their villages and speak to their peers about HIV/AIDS. The Peer Educators are given materials by the church such as posters, leaflets, exercise books and writing materials to assist them when speaking to their communities. The main objective of the Peer Education programme is to facilitate behaviour change. Knowledge about HIV/AIDS reduces stigma and discrimination against families living with and affected by HIV/AIDS.

Due to the increase in orphans in the country, we have set up the orphans and vulnerable children's project in Lae (PNG's second largest city). We currently have 18 children registered. These children have lost one or both of their parents due to HIV/AIDS. We provide food and clothes, and help the families in getting medicine. Counselling is provided to the children to assist them in dealing with the trauma of losing their parents. Once a fortnight, the children are brought together to play games and just have fellowship with one another. A number of them do not attend school as their families cannot afford the school fees.

I'll conclude by quoting from the Anglican Church of PNG, HIV/AIDS policy: "We hope for a future where we can help reverse the spread of the HIV and AIDS: where there is hope and not despair; love and not hate and healing not hurt; and where we can live out the call of Jesus to love one another as he loves us."



## SCOTLAND

### WAVERLEY CARE

Waverley Care has been working in the field of HIV/AIDS since 1989 and because of the nature of HIV infections in Scotland, especially in the early days when many intra-venous drug injectors were diagnosed, there has always been a strong

emphasis on working with children and the "affected family". (By "affected" we mean that there is a family member, usually a parent, who is HIV-positive.) We are fortunate that good ante-natal care and screening means that there are very few babies born in Scotland who are HIV-

positive in their own right. This has continued as the profile of the epidemic in Scotland has shifted, with increasing numbers of people from sub-Saharan Africa being diagnosed, many of whom have children.

Waverley Care has also consistently used a holistic approach and there has always been a strong emphasis on the spiritual care of those with whom we work. Since its earliest days, the organisation has employed a chaplain who has always happened to come from an Episcopal background.

Speaking to children affected by HIV, shows that children and young people have very clear ideas about what would make lives better for themselves and, indirectly, their parents and families. They include:

- the opportunity to talk about parental HIV openly
- more information about HIV illness
- better support and understanding in school
- better relationships with social

workers and health professionals

- more activities where they can meet with other children and young people in similar circumstances.<sup>1</sup>

HIV is still a relatively new phenomenon and we discover new information about it on a monthly basis. Whilst children do not need to be burdened by the detail of changes, they do want to know the basic facts in order to make sense of what is happening to their family member. Waverley Care is fortunate that our Children and Families Worker has been with the organisation since 1991 and is a trusted friend to the many children who over the last 16 years have come to her.

Waverley Care's experience is that it is all too easy for the needs of HIV-affected children to be over-looked or to get lost within statutory services where they are not a priority for support. Too often the support comes when the child is beginning to miss school or misbehave at school. Working with affected children at an early stage can help them and their parents come to terms with HIV in the family and move on to deal with all the other issues that face families in everyday life.

*"Listening to children and young people whose parent or carer is HIV positive", Children in Scotland 2002.*



### **POSITIVE HELP**

Positive Help offers practical help to people in Edinburgh living with HIV. It was established in 1989, originally through the

Scottish Episcopal Church, in direct response to HIV-positive people expressing a need for help with day-to-day living, and we continue to respond to that same need. By listening to what people tell us and responding to requests in an uncritical, non-judgmental way (with absolute clarity about the boundaries of our role), we are able to enhance the well-being of service users and their ability to manage better within their homes and communities; and to support a vulnerable, disenfranchised, often unpopular, population to gain control, dignity and independence within their lives. While public perception is that HIV is no longer a problem in the UK, especially with treatments being available, high numbers of new diagnoses continue, and care and support becomes increasingly complex. Positive Help currently has almost 1000 service users.

Children affected by HIV are difficult to support, mainly because stigma and fear of discrimination prevents both the children and the parents from asking for help; while ill-health, lifestyle and social disadvantage often make it hard for parents to keep up with the needs of a young, well family. Despite treatment now being available, many parents are still not consistently well and, sadly, the external social circumstances of these families have not changed significantly. Many children live with one parent, often in complex family units. Many of the service users who contracted the virus through injecting drugs in the 1980s now have second families, bringing some young children to our service. However, loss and anticipated loss remain ever present in their lives. This is especially so now with increasing numbers of parents co-infected with Hepatitis C, also contracted when they were injecting drugs, becoming very ill with advanced liver disease. This means long periods of ill-health and hospitalisation for the parents and therefore separation from their children. There are also renewed problems with childcare and foster care, with a fear of separation for the young people and the parents, not just about the children being taken away, but also about siblings being separated and the fear that this may become permanent. Current and problematic drug use had decreased for most of these young people but some parents are using drugs again to deal with the fear and stress of becoming ill and the possibility of dying.

Poverty, deprivation, social exclusion, discrimination, harassment, bullying and threats of violence are commonplace. The majority of children carry the burden

of secrecy about HIV in the family. Many develop inappropriate roles within the family to try to compensate for parental illness. The Positive Help volunteer befriender gives safe, supported time out for the child to talk, to be listened to and to feel valued. Uniformly, these children express a need to "belong" and to be "ordinary". Activities such as teaching them to swim and taking them to the cinema, enable them to build the confidence and skills that can help them join in. This in turn supports social integration and acceptance by their peers. It is known that the social and behavioural difficulties which manifest themselves within this group of children are greatly reduced by their involvement with Positive Help. Many families use the project where they are not in touch with other services or where others have failed to sustain contact. The impact on the welfare of the entire family is immense, and can help to keep families together. Our main aim is to try to prevent a further generation of damaged adults displaced within society, with complex mental health needs and dependency problems, and we work to give the children a sense of purpose, possibility and fun.

Our longest standing "befriending" relationship – 13 years – finally came to an end this year, with the now grown-up young woman leaving school and starting out on her adult life. The acknowledgement between the "befriender" and the young woman of the value of their time together was immensely moving but illustrated that if the work has boundaries and is supported, an ending can happen that is a positive and empowering moment for both young person and volunteer. When asked what it was that was most important in their time together, this young girl said that HIV dominated every aspect of her life, but in the "befriender" she had someone who knew about HIV in her family but allowed her the freedom simply to forget about it and go out and have fun and talk. "She made me laugh" was her final remark.



**THE NEXT FAMILY NETWORK NEWSLETTER** is to be on issues arising from the recent consultation, held in Seoul, on aspects of Violence and the Family.

## CANADA

The Teresa Group was founded in 1989, in cooperation with, but separate from, The Hospital for Sick Children in Toronto. It provides programmes and services for children living with or affected by AIDS and their families.

From some five families in the first few years, the Teresa Group now serves over 350 families with 670 children. In the early days, it cared for families with infected children, but as it grew, the needs of affected children began to be addressed. In order to receive service, a family will have one member under the age of 18 and one who is infected by HIV or AIDS.

In the early 1990s, many babies who were infected at birth died before the age of five, but with the advent of medications now given to mothers during pregnancy and to the baby for the first weeks of life, there are fewer deaths in early childhood and medication now keeps many children healthy. Some children who the Teresa Group has known for many years are now completing High School and entering post-secondary education.

An important programme developed by the Teresa Group is the provision of free infant formula for babies of HIV-infected mothers. Due to the high cost of formula, some mothers were considering breast-feeding their babies, despite the possibility of transmitting HIV to their children (around 18%). This programme now covers the province of Ontario and formula is provided for the babies for the first year of life.

As we better understood the emotional needs of children in families affected by HIV/AIDS, a group support programme started. Leading the Way began in 1995 and addresses the loneliness, isolation and depression so often experienced, as well as the stigma that remains among the public despite much education. Here the children may talk openly about living with the secrecy and stigma of this disease.

Asked how coming to the group sessions helped, one child answered: "Knowing that other people are like me with my health issues feels good, because those people don't seem different from people that don't have HIV/AIDS, so it tells me that that's the case with me too."

The beginning of spring always marks the start of another Leading the Way programme. Since 1995, the programme has supported children and youth affected by HIV/AIDS. Throughout the years, the facilitators have found many innovative ways to work with the children as they struggle to understand and cope with the impact of HIV/AIDS on their daily lives.

Two wonderful books, a quilt, masks, artwork, to name just a few things, have been produced by the groups. The results chronicle their own emotional journeys and serve as educational tools to other children and youth who perhaps do not have access to this type of support system. During this 2007 Leading the Way series, the children and youth have worked on the creation of a therapeutic garden. Thanks to the generosity of Riverdale Farm, the programme has been given some land to grow plants. The concepts of being connected to the earth, renewal and growth will be particularly significant to the children who have lost a family member to AIDS. Many of the children in the Leading the Way programme do not have access to gardens, or may not know how their contents can restore and heal. We look forward to getting dirty and watching the children and the garden grow and blossom.

Out of this experience, have come other supportive groups: for HIV-positive women during their pregnancies; for mothers with new babies; and for mothers with toddlers. They too can feel very lonely as they face the special problems that HIV brings to this time in their lives.

The Teresa Group also has a Food Bank that gives families food that can help with school lunches and with healthy snacks. At the start of the school year, a backpack is given to each school-age child with pencils, pens and paper. Getting through schoolwork can be very difficult, so a tutor can be provided to help a child through the curriculum.

There are more light-hearted provisions too, such as gifts for birthdays and other major events of the year and a big party with music and lots of wonderful food (donated) that happens towards the end of the year.

Here in Canada we are fortunate with our health care system and with the excellence of medical care at Toronto's Hospital for Sick Children. Together with them the Teresa Group is able to make a real difference in the lives of families affected by AIDS. Since I retired in 2000, it has been a real joy to see the continuing growth and development of the agency and to watch the children grow.

## USA

### Teens in the Valley of the Shadow of Death

Washington, DC is the nation's capital. It is also a geographic region with the highest rate of HIV infections in the United States. One in every 20 residents is HIV-positive and one in every 50 people in the city has AIDS. The disease has exploded among people who are poor, have been in prison, are addicted to drugs or alcohol and lack health insurance. It has especially impacted African-American residents. The problem is also increasing among people over 50 years of age and those under 25 years old.

Trinity Episcopal Church, a predominately black congregation including African-Americans and people from the Caribbean and Africa, decided that it would perform a special role amidst this health crisis. Trinity is also a parish that mobilised its members into community actions to reverse the rising rates of infection of HIV and AIDS in the District of Columbia. Trinity sponsored, a year ago, a citywide summit for religious leaders to organise the engagement of the faith community in combating the high level of infections. Last spring, the government of the District of Columbia's Department of Health ventured in a new direction and awarded a grant to the Trinity Development Corporation to organise a community outreach service programme to promote treatment and prevention of HIV/AIDS among District residents.

While Trinity's HIV/AIDS outreach programme targets the population most at risk – especially those between 25 and 40 years whose lifestyle increases their chances of being infected – Trinity's rector and pastor insisted that special services be organised and focused on prevention activity among young people under 25 years of age. Youth have the lowest rate of infection and are also most likely to adhere to knowledge and practices taught in prevention training. Special workshops were organised for various populations, and a special programme was developed to serve teens in the parish and community.

A group of a dozen teenagers were recruited and enlisted in a prevention training programme to develop the ability to be peer educators. A health specialist

from the Children's National Medical Centre and a prevention trainer from Planned Parenthood taught the six-hour prevention training workshop to the youth over two Saturdays. Parents became involved and attended two meetings in advance to determine the contents and scope of the training. Teens were taught how HIV spreads and what behaviors put people at increased risk of infection. Added focus centered on indirect risks like drug use or alcohol that can impair judgment and prompt more risky behaviours. The training included the correct use of condoms, given their proven effectiveness as a prevention practice. The training also emphasised that teens teaching other teens is the most effective prevention training. Once the peers were trained, a workshop was held in late fall to involve other teens in prevention training. Prior to the training workshops, a cookout was held featuring hot dogs, hamburgers, juice and fruit. The trained teens then conducted the prevention training of other youths in small groups. They wore T-shirts the youth designed themselves and that declared: "Peer Health Advocates Trainers" or PHAT, a term meaning "hip" or "cool". Concurrently, separate prevention workshops were held for parents, since parents also needed to be informed of effective prevention practices. Nearly 50 teenagers and parents attended the half-day prevention training event. Finally, a smaller group of teens circulated more than 500 flyers in the community surrounding the church to alert residents about the high rates of prevalence of HIV and AIDS in Washington. At the next day service of worship, the teens were celebrated for their service to their peers. Now the church is engaged in sending out its peer trainers to serve other faith-based and community groups to expand its prevention services among teens in the valley and shadow of death.

### Archbishop of Canterbury's Message for World AIDS Day

It is important that we do not allow ourselves to be paralysed by this challenge; people do not have to die – drugs and treatment are available – the scandal is that access is so often limited and it is hard to see where justice lies in the way resources are sometimes distributed...

The churches have not always challenged as they should the stigma that is attached to HIV and AIDS in many countries. They have failed to say that those living with HIV/AIDS are God's beloved children, with dignity, liberty and freedom. What is owed to them is what is owed to any human being made in God's image, and the more we are trapped by thoughts and images about stigma, the less we shall be able to respond effectively.

[www.archbishopofcanterbury.org/releases/071128.htm](http://www.archbishopofcanterbury.org/releases/071128.htm)

### PRAYER

ALMIGHTY GOD,

Look in your mercy upon children and all who suffer from HIV/AIDS – including those who do not know that they have become infected;

Give grace to children and relatives who look after members of their families who are too unwell to look after themselves, to the detriment of parenting, family income and schooling opportunities;

Protect those made orphans and strengthen their resilience;

Bless those who give appropriate medical treatment, sexual health education, pastoral counselling and practical support, and be close to those who, at present, are sadly beyond reach of these;

Energise your Church in its ministry of calm, care and compassion: and in its witness to the generosity of your saving love, especially to the young;

through Jesus Christ, our Lord.

**Amen**

Revd John Bradford

Visit the Family Network website: [www.iafn.net](http://www.iafn.net)

The views of individual contributors do not necessarily reflect those of the International Anglican Family Network.