

Village Service Trust

Newsletter

Spring 2015

A cruel inheritance

Of all the misfortunes that can befall one in life there can be few so unkind as to be born with HIV.

The babies of HIV positive women are at great risk of contracting HIV from their mother during pregnancy, during labour or through breast-feeding unless the mother receives proper treatment and guidance.

In theory in the age of HIV testing and effective anti-retroviral therapy, this is a condition that can be managed. In practice it is not so simple. Infants cannot be accurately tested before 18 months, while children with HIV may show no symptoms of Aids, and may not even develop Aids. But if HIV is there, eventually the disease will progress. It can be slowed or halted by drugs but for how long no one knows.

Jannani was born with HIV. Both her parents died from Aids and she lives with her grandmother. Jannani was identified as HIV positive when her mother died – it was only then discovered that her mother was HIV positive.

Jannani, now 13, has lost hope. She says: "Why should I take my medicine? I'm going to die anyway like my parents." She has dropped out of school because of illness, which is a result of failing to take of her medicine regularly. Her grandmother is very frustrated: "I don't know what to do to make her understand. She seems to have lost the will to live."

Jannani's story is sad, and sadder still there are many such stories. The good news is such tragedies can be prevented.

Our partner Arogya Agam has worked in this field for a number of years. Recently it secured a grant from Positive Action Children's Fund to enable the work to continue and VST is providing vital top-up funding.

The project aims to ensure that all pregnant mothers are tested for HIV, that suitable practices are followed when HIV mothers give birth, and to follow up all positive children and mothers to try to ensure that they receive the best available treatment from government services. It is important that anti-retroviral treatment to suppress HIV is taken, and taken regularly. Difficulties with maintaining treatment arise through lack of knowledge, discrimination at clinics and hospitals, poverty and the long distances some patients have to travel to treatment centres.

Our objective is to ensure that 90% of mothers will be on lifelong therapy at time of delivery and that 90% of the infants will have supervised anti-retroviral treatment.



A grandfather and grandson at Arogya Agam's HIV clinic

Photo: Richard Williams

A key feature of this project, like much of Arogya Agam's efforts, is the creation and support of community organisations, in this case networks of positive women. Each district network has about 60 members, many of them motivated through their own experiences of giving birth while HIV positive.

Arogya Agam trains the women as outreach volunteers who can identify families where HIV may be present and in need of support.

This could be financial support, referral for HIV testing and counselling, accompanying them to the appropriate services or taking up cases of discrimination. A big part of their work is to explain how anti-retroviral drugs can keep HIV at bay when taken regularly. Often parents find it hard to accept the need for treatment when no

symptoms of ill-health are present. Another focus is to keep children in school, especially girls who are at risk of being taken out of school to get married.

There is no doubt that children, girls in particular, whose HIV positive status becomes known in school face pressure to change schools which contributes to their dropping out. If they do not disclose the status they are unable to explain poor attendance and performance at school, teachers give up on them and dropping out increases further still.

John Dalton, who is based in India and advises VST, writes: "We are very excited that we have this project. All our research shows the need - so many HIV positive children are lost to follow-up. The positive women's networks have a great potential, past experience was really good."

The biggest problem is the reluctance of parents to give anti-retrovirals to healthy looking infants and young children – only a small percentage of HIV confirmed children are put on therapy before the age of two.

This is an ambitious project covering eight districts of Tamil Nadu – a much larger area than usual for us but the need is great. These eight districts have high incidence of HIV. The hope is that in three years the positive women's networks will have gained much experience and expertise and will be able to continue the work independently.

Mother-to-child transmission is the most common cause of HIV in children.

Perinatal transmission accounts for 5.4% of India's HIV infections.

Some 2.1 million people are living with HIV. Each year 130,000 people die from HIV/Aids related illnesses in India alone.

The project is expected to reach almost 7,500 children with HIV and have an impact on the lives of more than 35,000 people.

A space free from judgement

Dea Busk Larsen, a volunteer at Arogya Agam, reports on an initiative that helps young people cope with living with HIV

Life can be tough for children living with HIV. Many have lost one or both parents. They live in constant fear that others will discover their HIV status. And if their status is known they may face discrimination and harassment. Popular opinion about HIV has it that they are to blame and they worry that they might somehow infect others. This hampers them in making friendships, in learning and in becoming self-confident adults.

Camp Rainbow is a camp for adolescents living with HIV. Over two years it tries to teach them to be peer educators and leaders on HIV and other related issues in their community.

On the first day 22 participants arrived at their first camp feeling shy and uncomfortable. Even though the camp was only three days the transformation they went through was incredible.

'They had made friends who accepted them for who they are, which seemed special to all of them'

On the last evening when asked what was the best thing about the camp Siva Kumar answered: "At first I didn't want to come. I was afraid the others wouldn't like me but I've made so many new friends. I've even become friends with girls!" They had made friends who accepted them for who they are, which seemed special to all of them.

Thinking back on the experience Santosh Kumar shares how sad he was to leave the camp. He had made so many new friends and he was unwilling to leave them. "Camp was a space free from judgement. I really enjoyed the ritual when we took our medicine. We would stand together with our team, put one hand forward and in unison yell "red medicine" [red was the colour of his team] and then take the tablets. I still practise this at home and I don't feel ashamed of my medicine any more."

During the camp each participant was given an award for something they had done, for example by being a good friend, a keen listener or taking initiative.



Young people and staff at Camp Rainbow - a spell away from stigma, fear and discrimination, and a chance to gain knowledge and confidence

Siva Kumar's aunt explains how proud her nephew was: "He has shown his award to everyone, even his teachers. He basically carries it everywhere!" The acknowledgement that all the participants are valuable human beings was something that they don't always encounter. Too often positive children are undervalued with comments such as: "they will probably die young like their parents" or "it's not worth spending too much on their lives and education".

At Camp Rainbow the participants are trained as leaders and are seen as important people who can bring about a change in the way their communities think about HIV. Discrimination often stems from ignorance, which can be fought through knowledge and awareness.

On the first day a question box was introduced and the participants were

encouraged to ask questions about medication, treatment, relationships, sex and sexuality. Some of the questions about relationships were especially telling because of fears and doubts about their future. "Can people with HIV marry and have children? Can people living with HIV be in a relationship with a person who doesn't have HIV?"

Kamatchi Devi recalls how much new knowledge she gained and says: "In school we learn there are some things we can't talk about. It's considered bad and immoral to ask certain questions but at camp there wasn't anything we couldn't ask."

There is no easy answer to the marriage question. The official line is that HIV positive people should only marry partners who are also HIV positive. Sometimes marriages are arranged between young girls and much older HIV positive men.

There are also instances of marriages

between young people without disclosing the HIV status. This carries greater risk that the uninfected spouse will get infected – and any children too.

It also happens that love marriages or arranged marriages take place with the knowledge of the partner's HIV status. The official line is to use condoms always and not conceive children, perhaps adopting instead. In theory, if the HIV infected partner is taking anti-retrovirals properly then the risk of transmission is lower and condoms could be dispensed with on days when the woman is most fertile.

The Camp Rainbow participants spent three days learning and having fun in an atmosphere where they did not have to worry about HIV stigma and their troubled family situations.

Sex education is rarely taught in school, and even less about HIV, which

meant many myths were punctured doing this weekend. Along with acquiring new knowledge and building self-confidence the camp provided a safe and open space for the young people to learn about living with HIV.

We can safely say that everyone is looking forward to the next camp!

During the next two years there will be three more camps as well as four yearly follow-up days. One of the key objectives is to keep supporting the young people as they grow and new questions and concerns arise. The follow-up activities reinforce the experiences gained at camp and support the participants' gradual learning and development.

Most of Arogya Agam's work with HIV-affected children is funded by KNH, a German agency, while Village Service Trust makes a small contribution in addition to its more general support for Arogya Agam.



Murali joins VST board of trustees

It's truly an honour and a privilege to have been appointed as a trustee of Village Service Trust.

I come with 18 years of experience in the field of international development. My experience in international development is concerned with the use of media and information and communication technologies including the internet and mobile phones to improve people's lives. That is because I firmly believe that enabling a free and pluralistic media and communications environment is an important precondition to equality and social justice.

At the moment, I am a PhD researcher at the School of Oriental and African Studies. My research looks at everyday communicative practices of a Dalit community in Tamil Nadu. During my field work, I came to be in close contact with Arogya Agam and Vasandham Society (supported by VST) and I have witnessed their admirable efforts to improve the lives of Dalit communities.

As someone who comes from Tamil Nadu, but is now very much at home living in London with my family, I am very conscious that justice and equality is not possible unless Dalits can live without fear and with dignity. I am very happy that VST shares this vision as well.



Murali: vision for Dalits



A floral greeting for Arogya Agam's latest visitors: from left Gerti Wilford, Pat Monro and Jenny Band

'Their crusade is humbling and hopeful'

Gerti Wilford, psychotherapist and VST trustee:

Our partners in Tamil Nadu are keen to see the occasional visitor and have prepared a very comfortable and presentable small house in the grounds of Arogya Agam, where 3-4 people could spend a few interesting and enjoyable days.

Two friends and I have just returned filled with deep impressions of a groundswell change in the district where Dalits, Arunthathiyars and others, who find themselves living on the lowest rungs and below the Indian caste ladder in society. Their crusade against injustice and illegality is exemplary and despite setbacks, humbling and hopeful.

On this visit I was most impressed by the children and young people's groups whom we met. They could be tribal youngsters, from a village of Arunthathiyars, or children who were HIV positive or had lost parents from the disease. They not only learn how to speak out about what troubles them but also learn how to take responsibility for strategies that might help, taking care of their medication in case of illness or standing up for their rights, supported by the groups. The adult facilitators work with their parents, carers and schools. A recent camp experience, the first of its kind, had given them a lot of encouragement and trust in a future that had been uncertain before.

'The desire for change impacted me the most'

Pat Monro, lawyer and judge

My first (and hopefully not my last) visit to Arogya Agam has me fired up, stimulated, excited, overwhelmed; and above all has me reflecting 24/7 on the people with whom we were privileged to meet and everything that we observed.

From meetings with self-help children's groups, groups of positive children and their carers, and tribal children, to women's groups and a meeting with the Women's Federation, what impacted on me most was the desire for and determination to achieve change in society.

The issues that these groups face are endemic; discrimination with which the state colludes on the grounds of caste, gender, health, poverty and general vulnerability; the incidence of children who do not attend school, known as the 'drop-outs'; female infanticide.

The approach of the workers at the project is to empower those with whom they work, rather than for example applying for funds on their behalf; frustrating in the short term for the individual but in the long term avoiding a culture of dependency on the project.

Despite enormous obstacles to be overcome by the women and children we met, we were inspired by the conviction that whatever hurdles are put in their path, they will continue to campaign for their basic human rights.

'Personal insights that touched us deeply'

Jenny Band, textile conservator and beekeeper

It was impossible not to be overwhelmed by the situation, the culture, the challenges, the work VST supports there, and most of all, by the way in which that work is carried out. The scale, detail and extent of it would have been hard to assimilate had it not been for the care and thoughtfulness with which our trip was organised.

As it was, the hospitality and generous allocation of time we were given by key people enabled me to sample and digest a vast amount of information, impressions and discussion. We had focused and pellucid briefings from the staff prior to meeting the groups, where individuals often shared extremely personal insights into their private struggles and challenges. This was an extraordinary privilege and gave us insights that touched us deeply.

It is disturbing enough to read about the effects of corruption, domestic violence, caste discrimination, bonded labour, dowry pressures, early marriage, infanticide and other inequities which afflict so many of India's people. However, listening to children discussing some of these issues with an eloquence and wisdom so far beyond their years – and realising that these wise children are the ones left out of education and discarded by society – makes a very poignant impact.

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