Strengthening Women to Face the Challenges of HIV/AIDS

actionaid india

BANGALORE REGIONAL OFFICE

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ActionAid

ActionAid is a unique partnership of people who are fighting for a better world - a world without poverty. Its vision is a world in which every person can exercise his/her right to life of dignity. Its mission is to work with poor and marginalised people to eradicate poverty by overcoming the injustice and inequity that causes it. It believes that by working together local communities, organizations and governments can bring about real change to the lives of poor people. ActionAid, founded in 1972 in UK, is an International Development Agency that works in over 40 countries in Asia, Africa & Latin America. It creates a North-South solidarity by linking people across the globe.

ActionAid India was started in 1972 and works across 22 states in India from Manipur in the north-east to Leh district in J&K and Kerala in the south. With guiding principles of the Rights Based Approach, AA India programs reach out to more than 4 million people from the poorest communities in India.

Objectives

- Enable basic rights for the poor
- Build lasting institutions of the poor
- Address the root causes of poverty
- Change the forces that perpetuate gender inequity

Principles

- Take sides unambiguously with the most marginalised communities
- Influence state policies, laws and programmes in favour of the poor
- Involve the people in poverty, at every stage of planning, implementation, monitoring and evaluation of programs
- Transparency and accountability to the poor communities with which we work

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Voices of Affected People

"We had helped so many people in trouble. Now they don't even acknowledge our presence."

"I can't afford to earn enough for our daily food. How am I going to buy medicines?"

"The only place I feel secure is when we positive people meet. This is the only time I am not worried about any one pointing fingers at me and making fun of me."

"I love to go to school. I got very good marks. But why don't the other children play with me?"

"No one gives me a job. Should I stop telling my prospective employees about my being HIV positive?"

"Why should I tell you the truth? You will go and tell the world and I will lose my government job!"

ActionAid and HIV/AIDS

ActionAid understands that poverty and marginalisation are produced and reproduced by the systematic denial and violation of rights of certain groups of people. HIV's relation to poverty, marginalised groups and violation of human rights makes HIV/AIDS relevant in ActionAid's work. Addressing vulnerability to HIV becomes relevant in the context of women and children, particularly of the marginalised groups like sex workers, migratory populations, the disabled people, the urban homeless, people in prisons, drug users or victims of disasters and wars. Even though HIV does not discriminate between rich and poor, poverty and marginalisation makes one vulnerable to HIV. ActionAid has been associated with HIV/AIDS since it's financial and technical support to The AIDS Support Organisation (TASO) in Uganda in 1987. ActionAid considers HIV/AIDS not only as a health issue but more importantly a poverty, gender and development issue.

ActionAid's Strategies for Combating HIV/AIDS

- ActionAid recognizes the different needs of women, men, boys and girls and will seek to challenge the power imbalances between these groups where they negatively impact upon people's vulnerability to HIV/AIDS.
- ActionAid believes that People Living with HIV/AIDS (PLWHAs) have a central role to play in prevention and in alleviating the impact of the epidemic and will make all attempts to promote their involvement in the decision making and management of HIV/AIDS programs.
- ActionAid advocates for an end to the violation of the rights of PLWHAs and affected families and will promote the special needs of those who are infected and affected, particularly children who are left orphaned as a result of AIDS.

- Equally importantly ActionAid recognizes that the majority of people are HIV negative and have a right to be protected from infection.

ActionAid India - Addressing Issues of HIV/AIDS

ActionAid India initiated its HIV/AIDS programme in 1998. AA has been providing technical and financial support to project partners, developed communication material, sensitised the staff as well as staff of project partners in helping them to integrate HIV/AIDS work in the Development Areas (DAs).

Today AAI supports projects that focus on rights issues, care and support as well as prevention. These projects involve sex workers, migrant workers, drug users, networks of infected/affected people and children of many of the above groups of people. AAI works with sex workers in the four metros of Delhi, Kolkata, Chennai, Mumbai and in Bangalore, Hyderabad and Lucknow. ActionAid India also supports and promotes Networks of Positive People such as the Manipur Network of Positive People in the North East, En-joy, a network of infected People in Kolkata, and Milana - a network of infected/ affected women in Bangalore.

ActionAid has gained reputation for its long engagement in combating HIV/AIDS in Africa. ActionAid is also known for its two highly participatory approaches namely REFLECT and Stepping Stones (SS). India uses both these tools to address issues of HIV.

"Experience has shown that the best way to respond to the challenge of HIV/AIDS is to act locally and collaborate globally"

Prime Minister Atal Bihari Vajpayee,
Parliamentary meet on HIV/AIDS,
New Delhi, 2002.

Grave Situation in Karnataka

HIV/AIDS has left almost no state in India untouched but Karnataka State today ranks the third highest in prevalence. According to the Karnataka State AIDS Prevention Society (KSAPS), there are an estimated 400,000 to 600,000 PLWHAs. The statistics until September 2003 show a startling picture and the common man is just starting to understand the gravity of the situation.

- AIDS Deaths: 201
- AIDS Cases: 1,849
- Diagnosed HIV Cases: 23,063
- Undiagnosed Estimate: 400,000-600,000
- 80% are in the 20-40 groups
- Rural incidence much higher in under-20s and above 30s
- Highest incidence in Chamrajnagar, Bijapur, Raichur
- High prevalence districts are Bangalore Urban, Bellary, Belgaum, Bijapur, Chamrajnagar, Dharwad, Dakshina Kannada, Gulbarga, Mysore, Udupi
- Districts like Dharwad estimated to have over 10,000 persons with HIV though most are unaware of it
- Heterosexual transmission is the most common route of HIV
- HIV incidence among high-risk group varies between 11% to 15%
- 1.7% prenatal transmission
- Mother To Child Transmission (MTCT) may result in over 7800 children being born with HIV infection this year

"The fatal nature of AIDS, the stigma attached to it, its association with condemned behaviour, has produced a devastating and cruel scenario. The situation has changed rapidly, necessitating a more radical and broad-based approach.

I appeal to all sections of the Society - government, NGO groups, private sector and all concerned citizens to support the Government's efforts."

Shri. S. M. Krishna,
Chief Minister of Karnataka,
Annual Report, KSAPS, 2002

Significance of the HIV/AIDS Trends in Karnataka

- Number of HIV infected individuals is showing a steady increase over the years.
- Number of HIV infected women is on the rise. Most report sexual contacts with a single partner - their husbands.
- Number of children born with HIV is on the rise and MTCT needs to be controlled.
- Rate of infection among STI clinic attendants is also increasing and points to high rates among people with "high risk" behaviour.
- Number of deaths due to AIDS is on the rise and points to considerable progress of the epidemic.
- For every reported case, there will be many unreported cases. The figures may actually be higher than what has been estimated.

HIV/AIDS – The Karnataka Dimensions

Karnataka has its own unique features in respect of its geographical location and social equations. The dry areas of the north, the caste systems and cultural traditions all influence the lifestyle of the people in Karnataka. The other factors are unemployment, lack of education, poverty, alcohol etc. All these factors affect the spread of the HIV infection.

Poverty, Drought and Migration: The 'Push' Factors

The northern districts of Karnataka where the prevalence of HIV is high, are also home to more poor people. This poverty belt of Karnataka is drought prone and people migrate to neighbouring states like Maharashtra and Andhra Pradesh for about 6 to 9 months each year, in search of work. Karnataka faced its third consecutive year of drought in 2003 with the State Government declaring 25 districts as drought-affected. Farmers with small landholdings and landless labourers bore the brunt and newspapers have reported the spate of suicides which took place over the year. This has led to a majority of its village populations being forced to migrate to cities in search of food, water and employment. A significant number of people who migrate are in the most productive age group of 15 to 45 years which is also the most susceptible to STI and HIV.

Opportunities in Cities and Urbanisation: The 'Pull' Factor

Native unemployment makes people look for opportunities in larger cities. Bangalore, the silicon valley of India is also its fastest growing city and a very attractive destination for most people. Mumbai, the economic capital of the country is just a few hours away, especially for people in north Karnataka. People in districts around Karwar can easily walk across to Goa, the sex capital of India. Karnataka has a very high urban population of 34% as compared to the national average of 28%. Increased rural urban migration has lead to about 40% of urban population living below the poverty line which is higher than the national average of 32%. Uneducated and unskilled people take up any kind of available employment and are often lured into sex as a livelihood option.

Caste Dynamics:

Inherited inequities of caste is manifested in the practice of untouchability and bonded labour in many districts of Karnataka and continues to be a major factor determining a person's available choices of occupation. The scheduled castes today constitute about 17% of the state population and bear the burden of a legacy of social degradation. However, when they move away from traditional confines, they also breakfree from the shackles of caste and religion. Moving from 'humble hometowns' into large 'happening cities' also provides an anonymity that could influence people, especially the youth, to indulge in adventuresome and risk taking behaviour.

Alcohol, Gambling and Drugs:

The process of liberalisation and globalisation in a state of inherent inequities and wide disparities has brought in a state-aided demand for "marketable" produce including alcohol, which is freely available in the remotest areas. Substance abuse, including injecting drug use is rising rapidly in the cities, especially among the youth in Bangalore. Even platform and street children are being pulled into the vice by drug peddlers. There is a strong link between the use of intoxicants like alcohol/

drugs, gambling and unsafe sex. Added to this is the lure of online lottery which is cleverly packaged as 'entertainment for primary education' by the government. This heady mix of alcohol, drugs and gambling, preys on the weaknesses of the people by pandering to their desires and leads to increased violence, risky sex and crime. Factors to fuel risk taking behaviour such as visits to brothels, multiple partners and gay behaviour is also induced by conflict with the law, workplace harassment, loneliness and peer pressure.

I, Kamala, am from a small village in North Karnataka. I was married to a person who was working in Bangalore with a builder. I had thought that I would also go to Bangalore with him but he left me at his parents' house and went away on his own. He would come to meet me once in a couple of months. I was tortured by my in-laws for dowry, not doing enough work, talking to my parents etc.

I complained to my husband about their behaviour but he refused to take our daughter and me to Bangalore. He said that there were many people like him who had their families in their hometown and lived in the city looking for a livelihood. This went on for about 10 years.

My husband used to be quite sick. Then one day, he fainted at work. His supervisor rang me up and finally I went to Bangalore. My husband was very sick and he had been tested positive for HIV. I had no idea about the infection and no one was ready to tell me about it. I thought it was like any other disease and I decided to look after him. His friends convinced him not to send me back to my in-laws' place. We rented a house and now live there.

His friends took me to a counselor. They explained to me about the infection and the precautions that had to be taken. I was tested and found positive. My husband's friends have been very good to me. They have been my only help in an unknown city. My family has no idea about the kind of infection we have and we are not ready to tell them, as there will be more problems.

I have noticed that many men live on their own in Bangalore and many of them have similar problems like my husband. I wonder if they are HIV infected too!

- Kamala, Bangalore.

Women more Vulnerable to HIV

Gender issues contribute greatly to unequal power relationships and vulnerability to HIV. Let us look at the factors that put women in Karnataka at greater risk.

❑ Patriarchy

The state's adverse sex ratio, low female literacy rate and high maternal mortality rate are clear indicators of the low status of women in a patriarchal society. According to the 2001 census, the sex ratio (number of females per 1000 males) is 963 for the state as a whole. A very disturbing trend is the decline in sex ratio in the 0-6 age group from 960 to 949 over a ten-year period. There are also large differences in the rates of school enrolment between boys and girls (13%), and male-female literacy levels (16%) in Karnataka, at the state average. The statistics paint a clear picture of male domination that leave girls and women with little or no say in matters of education, occupation and marriage. This also means they have no negotiating power in sexual relationships which puts them at risk of HIV.

❑ Child Marriages

In the tender age group of 10 to 14, 4% of all girls in the state were married as per the 2001 census. While figures of child marriage were above the state average in the districts of Belgaum, Gulbarga, Raichur, Bellary and Bidar, Bijapur with 12% topped this statistic. In most cases the husbands are much older men who have experimented with sex and multiple partners and pass on STI including HIV to their young wives.

I was 12-years old when I was married to a 26-year-old truck driver. By the age of 20, I had four children. My husband used to drink and gamble. There was very little money given to me. Violence was a way of life with him. I was told that he visited a few other women. When I questioned him about this he just hit me! He started falling sick often and with the help of my sister-in-law, I got him to undergo a few tests. This showed that he was HIV positive! Once I came to know the meaning of this infection, I moved back with my mother. Here I was shocked that my brothers, who were very good to me earlier, wanted me out of the house. So I took another house and started living there working as a vegetable vender. I am also infected and so are my children. I would look after my husband whenever he visited me but he would disappear once he was better. When he was very sick, he was admitted to the hospital where he passed away one day.

I am 26 years now with four sick children and myself to look after. I wonder if there is a miracle that will help me. **- Lakshmi, Bangalore.**

❑ Devadasi System

The cult of dedicating young pre-puberty girls to a deity or Goddess Yellamma, makes her a 'devadasi' - the handmaiden of God. In reality, she lives the life of a sex worker, used and abused by men and society. The Karnataka Devadasis (Prohibition of Dedication) Act, 1982 acknowledges in its introduction that "the practice leads women to a life of prostitution" and has legally abolished the system. Yet the practice in its most dehumanising form of child and women abuse continues in the areas bordering Karnataka and Maharashtra. The devadasis are looked at as social outcasts who cannot marry and are obliged to satisfy the men who visit them for sex. Many are sold into the brothels of Mumbai where, according to an UNAIDS report in 2002, over 50% CSW are HIV infected. The poverty dimension is clear even here - devadasis are found only among three scheduled caste communities in six districts of Karnataka namely Raichur, Bijapur, Belgaum, Dharwad, Bellary and Gulbarga. As per the Joint Women's Programme, almost 92.5% are illiterate and 38% have a monthly income of less than 500 rupees. The miserable conditions affect the health status of these women and it is rare to find a devadasi above 50 years of age.

❑ Trafficking and Commercial Sex Work

"I am eighteen years old but have been through hell. Trafficked at 14 for sex work, forced to abort twice and then separated from my newborn son. Rescued in a police raid, I am staying at a good home run by an NGO, but have no family to return to. I often fall ill and am under treatment. I feel depressed to think about my future."

-Kavita, Mysore.

The Indian Government's Social Welfare Board lists Karnataka, Andhra Pradesh, Maharashtra, Tamil Nadu and Uttar Pradesh as the 'high supply' zones of prostitution. In Karnataka, Belgaum, Bijapur, Hubli - Dharwad and Gulbarga are the vulnerable areas where the trafficking structure operates at various levels. A survey puts the number of sex workers in Karnataka at 2,50,000 with more being inducted each year. The problem is aggravated with about an equal number of children of sex workers also caught up in the trap of poverty and exploitation. The factors behind the rapid rise in human trafficking are the increasing levels of poverty, ignorance of rights because of illiteracy, a mindset that discriminates against the girl child, unemployment, tourism, migration, social and religious customs, consumerism and attraction to the glamour world.

❑ Violence Against Women

"My father had some agricultural property but never ever worked. All he did was drink and beat my mother. When we rushed to her aid, we got the thrashing too. Instead of being sent to school, we girls were made to work in the fields and in the home. Yet, my mother, elder sister and I were often thrown out of the house by my father and would seek refuge in my grandmother's house. The cycle of alcohol and violence finally ended after a particularly brutal assault on my mother which resulted in her deciding not to return back to my father's house. But we girls were a burden on my grandmother and so were married off to older men. My husband was 55 years old and his children were my age. I hated him.

-Mamta, Mysore.

Domestic violence dis-empowers and threatens women and poses a greater risk on women. Often, the cycle of violence and exploitation continues at the matrimonial home and workplace where women are unable to protect themselves.

Garment Industry Link to Trafficking and HIV

According to DISC, an NGO working with garment workers, a large number of the sex workers in and around Bangalore are from the garment industry. Most of the women workers come from poorer sections of society and travel long distances from the outskirts to the factory. They have long working hours and are forced to stay back late into the evening to satisfy unrealistic production requirements. Most supervisors or masters however are men. They create problems for the women workers and sexual molestation at the workplace is rampant. On their long journey back home too, women are accosted at late hours. Girls who do not comply with male advances at work are harassed and thrown out of their jobs on some pretext or other but those who do comply enjoy many benefits. They also have no problems in getting leave, not meeting with production deadlines, coming late to work, etc.

Once initiated into sex work through exploitation, many take it up in the evenings for monetary gain and families are unaware of it because they blame work schedules for coming home late. Even more disturbing is the fact that many young unmarried girls are trafficked to brothels in Mumbai and Delhi on the false promise of 'handsome salary for less work in garment industries of bigger cities'.

❑ Biological Aspects

Although HIV initially started as an infection affecting Men who has Sex with Men (MSM), today 43% of the world's infected people are women. In South and South East Asia, women are at a five times greater risk than men of contracting HIV. A study in India showed that almost 90% of women who had HIV reported sex with just one partner - their husband. Yet the rates of infection among women is rising and accounts for 25% of all new infections in India. Anatomically and socially, they are more vulnerable and this is a very disturbing news because infected mothers can transmit HIV to their children before and during childbirth and also after through breastfeeding. Aggressive Anti Retroviral Therapy can prevent Mother To Child Transmission but the cost factor is as always a handicap.

Women traditionally are caretakers of children and family, hence their well-being is essential for the welfare of the family. Besides being highly vulnerable to the infection itself, the women have to carry a lot of burden on their shoulders. In case one or more people in the family are infected, the women takes on more responsibility.

- ❑ They have to care for the sick in their homes.
- ❑ They have to work to keep the money flowing in.
- ❑ If they themselves are infected it is difficult for them to undertake physically taxing jobs.
- ❑ They have to face the stigma of being a HIV positive person or a family member of a HIV infected person.

"The illiterate are more vulnerable. Women are infected with HIV at a much younger age than men..."

Vandana Gurnani,
Project Director, KSAPS
November 2003

The Silver Lining

"It has been recognised that when human rights are protected, fewer people become infected and those living with HIV/AIDS and their families can better cope with HIV/AIDS."

From the National AIDS Prevention & Control Policy 2002, NACO, India

The presence of HIV is like the sword hanging on one's head. Giving hope to the increasing number of People Living with HIV/AIDS, there are initiatives taken up by the State government and NGOs.

The Karnataka State AIDS Prevention Society (KSAPS) was set up by the government in 1997. The programme of KSAPS consists of Priority Targeted Interventions, IEC, Blood Safety, Voluntary Counseling and Testing Centres, Low-cost AIDS Care and Support, Programme Management, Institutional Strengthening, Operational Research, R&D and Training Programmes. It will also take up education programmes in schools and government and public sector undertakings. KSAPS works in collaboration with other organisations - governmental and non-governmental - to attain its aims.

NGOs: There are many committed grass-root organisations like Samraksha, Freedom Foundation, Swasthi, SPAD, Snehadaan, Sangama etc., which supports PLWHAs. Their activities range from counselling for the HIV positive people and their family members, medical help in the form of expertise and medicines, hospices, drop-in centres and community care and support to the infected people.

Hospitals: Hospitals like NIMHANS and BOWRING are equipped to treat HIV infected people. They also have counselors who provide inputs and references to organisations/institutions who will be of help apart from the medical help they get from the hospitals.

Networks: There are networks of infected people like KNP+ and Milana, which focus on better quality of life and empowerment of PLWHAs. They provide space for PLWHAs to gather together, to share and discuss issues, create awareness of legal rights, organises trainings in various aspects to help the positive people help themselves.

INGOs: There are international organisations like ICHAP and ActionAid who are committed to the cause of HIV. The India-Canada Collaborative HIV/AIDS Project (ICHAP), established in early 2001, is a five-year project funded by The Canadian International Development Agency (CIDA). ICHAP provides technical assistance to national and state-level governmental and non-governmental organisations in the project states of Karnataka and Rajasthan. Their main focus is on enhancing capacities, epidemiological surveillance, targeted interventions, prevention and control of sexually transmitted diseases, care and support and operational research. This project also is executing demonstration projects for HIV/AIDS.

Legal Support: The National Law School of India University and The Alternate Law Forum (ALF) looks into the legal aspects of HIV/AIDS affected people and supports them in cases of denial of rights.

Media: The media in general has played a positive role on the HIV-AIDS issue in Karnataka. The print media has regularly reported on govt. and NGO initiatives and activities and highlighted shortcomings in blood safety, hospital care and facilities. Most reputed Dailies in English and Kannada have tried to enlighten the people on the need to end discrimination of PLWHAs.

Anti Retro Viral (ARV) Therapy - Reasons for Hope?

If India and other nations can find a way to take up the CIPLA offer for ARV therapy which hinges on successful funding, it could spell hope to millions of people. Harping on prevention and not on care is an example of a short sighted policy. The bold offer by the Indian Pharmaceutical manufacturer CIPLA to provide the cocktail drug 'Triomune' at cost to wholesalers, governments, and non-profit charitable organizations is good news.

There is some news on the vaccine development front also. After years of pessimism and setbacks, the new influx of money from government and non-government sources has created a number of very large and international collaborations who are investigating/developing/using innovative techniques for making vaccines.

India is readying for clinical trials of a HIV/AIDS vaccine that is under laboratory and animal trials in the USA amidst controversy over using human volunteers from underdeveloped countries as 'guinea pigs'.

An Indian scientist at the Kolkata-based National Institute of Cholera and Enteric Diseases (NICED) has jointly developed the vaccine with Boston-based biotechnology firm Therion Biologics.

However there is no denying that the world needs an HIV/AIDS vaccine and field testing is a necessity. It is also important to ensure that the AIDS vaccine, when developed, is made accessible and affordable to the poor.

Miles to Go...

There is a lot that is being done for the infected and affected people. However, most of the efforts mentioned above reach only the urban areas, particularly Bangalore. There has to be concentrated effort to intervene in the areas of localised epidemics to contain the infection and help those already infected.

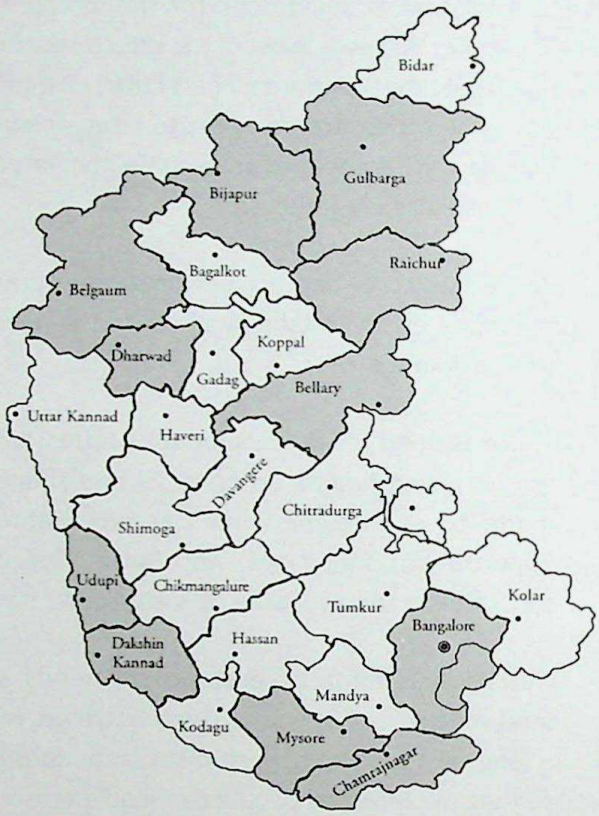
- There has to be more co-ordination and an up scaling of effort to take this help to the needy in the rural areas.
- There is need for development of infrastructure for bettering health services. Efforts should be made to ensure medicines are available for opportunistic infections. Anti Retro Viral drugs should be made available at subsidised rates.
- Nutrition is another area which needs state intervention and support. Good nutrition will go a long way to keep opportunistic infections away so that the infected people can lead a reasonably healthy life.
- There has to be in depth research and documentation. This will help in knowing the reality of the situation of the spread of the infection, the status of the PLWHAs and the kind of help they need could be determined.
- The media has been positive and the plight of innocents and children with HIV/AIDS has been widely reported. Nevertheless, these reports need to be more researched and analytical in nature.
- The civil society is aware of the HIV infection and the problems that will arise with the spread of this infection. They are sensitive but not proactive. They need to be more involved in the awareness programmes. It is the society that can stop discrimination and help infected and affected people to earn a living, seek help and live a fearless life.
- There has to be more and better care and support. The infected and the affected are both in need of this. There should be easy access for this kind of support at all local hospitals.
- It is important to place PLWHAs at the centre of decision making to effectively combat the growing HIV/AIDS epidemic.

ActionAid's Work in Karnataka

STATE LEVEL CONSULTATIONS: ActionAid started its work on HIV/AIDS in Karnataka in 2001. It started with two state level consultations on HIV/AIDS in Karnataka in collaboration with KSAPS (Karnataka State AIDS Prevention Society) and ICHAP (India-Canada Collaborative HIV/AIDS project.)

TOT ON STEPPING STONES: In collaboration with ICHAP, ActionAid also conducted a Training Of Trainers on Stepping Stones for about 40 people, ICHAP and AAI partner staff and AAI staff. Stepping stones is a training package on gender, communications and HIV/AIDS developed by ActionAid in Africa. This led to the production of an Indian manual on Stepping Stones which is also translated into Kannada. The manual is currently being field tested in both ICHAP and AAI project areas.

PRODUCTION OF A BOOK: The regional office played a key role in the production of the HIV/AIDS book - TIME TO ACT, produced by ActionAid Asia. The South Asia Chapter of the book was compiled by Christy Abraham and Meghna Girish.



Grey areas in map show high HIV prevalence districts in Karnataka.

Future Plans for ActionAid

- Strengthen Milana and other networks
- Form smaller Self Help groups - atleast four of them
- Move into more rural areas of Karnataka
- Undertake research and documentation on the issue
- Take up discrimination issues through the network
- Stepping Stones to be used more widely.

Milana – The Family Support Network of Infected/Affected Women

Milana, the network of infected/affected women in Bangalore is a Family Support Network, promoted by ActionAid, Bangalore Regional Office. The focus is on the "quality of life" of the HIV positive people with a special focus on the needs and rights of women and children.

Milana at a glance	
Families	: 125
Infected Couples	: 12
Infected widows	: 65
Non infected widows	: 6
Children	: 235
Infected children	: 50
Orphans	: 22
Infected men	: 18

- Milana is the **Meeting** place, which provide a space for individuals and families to come together to observe, share and understand the challenges and opportunities in the lives of PLWHAs, with a special emphasis on women and children.

- mIlana: Here the emphasis is on **Interaction** where members provide and receive counselling and develop a peer support group. Counselling for Confidence Building is the foundation of the Network. They act as care givers for others during crisis situations.

- miLana: **Learning** and Education is an integral part of the Network. Children are encouraged to go to school irrespective of their HIV status. Support is provided to non HIV children to cope with the HIV status of parents or siblings and sexual health among adolescents.

- milAna: **Acceptance,** of the status of HIV has to come from within. Discrimination by family and community has to be removed. The Network will strive to address discrimination issues by dealing with it upfront. Support to women who face discrimination will be given by other network members.

- milaNa: The keyword in Milana is **Nutrition** is Health. Nutritional support is provided to families who are members of Milana. This helps families not only to cope with health issues but in many cases to gain the confidence of other family members who accept them as contributing members of the family.

- milanA: **Articulate** - to break the culture of silence among women, to empower them, to ascertain their rights within family, community and society at large. Capacity building of women on rights issues, on skill development etc. are hence part of the process.

A STUDY OF MILANA: A detailed study of 30 families involved was taken up to find out their own perceptions about HIV, understand the life of the infected people, and how they cope with the challenges that have come about after being infected, using the case study methodology. The analysis of case studies of women shows some expected and unexpected trends.

- ▼ Physical violence has been reported by 47% of them. 40% stated that they have been verbally abused and mentally tortured.

- ▼ 33% of these 30 members are illiterate, 50% are able to read and write only. 17% had been to college.

- 80% of the people said they came from economically poor and insecure families.
- In 18 cases, the male members of the family have been casual labourers/migrant workers/drivers who have spent a lot of time outside the house. Drinking, smoking and gambling have been a part of their lives. Even in those who had a steady job, these vices have been reported.
- 50% of the women members have picked up a temporary job after their husbands have passed away to make ends meet, mostly as domestics, vendors etc. 5 of them have permanent jobs. There are two who have contractual jobs i.e., they have a job but are not eligible for perks like medical help.
- About 98% of them had no idea about HIV/AIDS. Most of them had not understood it till they had been counseled after they had been infected.
- Another major aspect of HIV infection is the discrimination that they have to face. This is the reason why they never tell others about their infection because they fear becoming outcasts. 12 of them have not even told their families. 2 of them have been open with their infection while the rest have told only to their immediate family.
- All of them feel that medical help - consultation, tests and medicines are very expensive. This takes away most of their little savings. There comes a stage where they give up and stop medication completely.
- All the members in the study said that initially they approached the local doctor for help. When abnormalities in their cases were discovered, correct information was not given. All of them feel that the doctors should be able to guide the patients to hospitals with infrastructure to deal with HIV infection. This would save time and money.
- While many of them said that the hospitals where they finally went looked after well, there are 6 members who specifically mentions discriminating attitude of the hospital staff.
- Lack of education, job skills and poor health makes it very difficult for positive people to find jobs. With no money coming in, it is difficult to live. Nutritive food and medicines that a positive person needs is then a dream.
- Children are the first to get affected with the money crunch in the family. They have to dropout of school and have to go to work.
- The members have been of the firm opinion that counselling has helped them a great deal. The project office has become a place where they meet and let their hair down. A woman said that one day with all her friends at the Milana office helps her to get through a fortnight without feeling depressed.
- Once the members have got over the initial shock of being infected with the HIV, they have accepted it and now look forward to live a normal life - or at least as normal as they can live.
- It has been noticed that those who are educated have lesser problems coping with the infection. They can take calculated decisions and try and make their life less stressful. Among these people, those who have permanent jobs lived a better life.
- It is also important to note that 20 members of the sample group come from large families but have only one/two children. This trend is seen across the board, education, poverty, exposure not withstanding.

This study was conducted in Bangalore but can be a reflection of the life of the PLWHAs in Karnataka. We need to explore further, through systematic and more closer interaction with PLWHAs, to create policies and strategies in favour of PLWHAs.

What One Needs to Know About HIV/AIDS

What is HIV/AIDS?

- HIV is the human immunodeficiency virus that attacks the immune system of a person.
- This infection develops into AIDS - Acquired Immuno Deficiency Syndrome - in the last stages.

Spread of HIV/AIDS

- Through unprotected sex - oral, vaginal and anal.
- Drug injection by used needles having contaminated blood.
- Transfusion of infected blood or blood products.
- Through Mother to Child Transmission.

HIV does not spread by

- Shaking hands
- Travelling together
- Eating in the same utensil
- Working along with infected people
- Hugging and kissing
- Mosquito bites
- Through water or air.

One must protect oneself by

- Abstaining from casual sex
- Have monogamous sexual relationship with uninfected partner.
- Having protected sex - use condoms each time and every time.
- Do not use previously used needles.
- Get blood and blood products tested for HIV infection if they are to be used for transfusion.
- Influence of alcohol/drugs could lead to unprotected sex. Avoid it.

What to do if tested positive for HIV

- See a health care professional for a complete medical work-up for HIV infection and advice on treatment and health maintenance. Make sure you are tested for TB and other STDs. For women, this includes a regular gynaecological exam.
- Inform your sexual partner(s) about their possible risk for HIV.
- Take precautions to protect others from the virus.
- Protect yourself from any additional exposure to HIV.
- Avoid drug and alcohol use, practise good nutrition, and avoid fatigue and stress.
- Seek support from trustworthy friends and family when possible, and consider getting professional counselling.
- Find a support group of people who are going through similar experiences.
- Do not donate blood, plasma, semen, body organs, or other tissue.

What we can do to be a caring community

- Stop discrimination
- They do not need your pity. Treat them as productive human beings.
- Do not condemn them.
- Support the infected people as best you can.
- Do not shy away from discussing HIV infection. It is not a taboo subject.
- If someone comes to you for help, give correct information or direct them to organisation/trusts/hospitals for more help.

Helplines in Karnataka

Name of Trust/Foundation	Phone No.	e-mail
AIDS Counseling Care Education & Prevention Training Society (ACCEPT), Bangalore	80-8465418 / 8445202	raccept@yahoo.com
Asha Foundation, Bangalore	080-3435888	ashaf@satyam.net.in
Ashakirana, Mysore	0821-496677	
Belgaum Integrated Rural Development Society (BIRDS), Belgaum	08332-384678 / 388622 324435	
Bhoruka Charitable Trust, Bangalore	080-2222311 / 2291738	bctbng@bgl.vsnl.net.in
Bhoruka Charities, Bangalore and Gulburga	080-2270577 / 2272271 Gulbarga - 08472 - 453208	bhoruka_charities@yahoo.com
Catholic Health Association of Karnataka (CHAKA), Bangalore	080-5506779	
Citizen's Alliance for Rural Development & Training Society, Mangalore	0824-431215 / 431947	citizensalliance@yahoo.com
Freedom Foundation, Bangalore	080-5449766 / 5440134	freedom@bgl.vsnl.net.in
Grama Swaraj Samithi, Bangalore	080-5351756	
Infant Jesus Children's Home, Bangalore	080-8465948	
Jagruthi, Bangalore	080-2860346 / 5266132	jagru@vsnl.net

Name of Trust/Foundation	Phone No.	e-mail
Karnataka Integrated Development Services, Dharward	0836 - 74087 / 744196	kids_dharward@hotmail.com
KNP+ Bangalore	080-2120409 / 3305479 [R]	knpplus@vsnl.net
Prajna Mangalore	0824-432682 / 0824-432133	prajnacc@sancharnet.in
Samraksha, Bangalore	080-2238297 / 2279318 Fax: 2993710	
Samuha - Samraksha, Bangalore	080-3546973 / 3546965	samraksha@vsnl.in
Snehadaan, Bangalore	080-8439516	
Society for People's Action for Development, Bangalore	080-5471680	spadorg@satyam.net.in
Suraksha, Bangalore	080-3223669	suraksha-harini@yahoo.com
Truck Workers Welfare & Charitable Trust, Bangalore	080-6612126 / 6678526	
Ujwala Rural Development Service Society, Bijapur	08352-5713 [R] / 22972 [O]	

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The photographs of people in this book do not necessarily match the text. They are in no way indicative of HIV Positive status.

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