Give a future for 950 Indian kids living with HIV

This project is operated by Arogya Agam, an Indian NGO along with a consortium of five District branches of “Positive Women’s Network”. The project works in five Districts of the South Indian state of Tamil Nadu. We work with 950 vulnerable children living with HIV.

Arogya Agam works with the most disadvantaged people, giving priority to women and children. Our main strategy is to encourage and support community volunteers and community based organisations to advocate for their rights and entitlements.

The District Positive Women’s Networks are members of the Indian National Positive Women’s Network.

We work in the Districts of Theni, Tiruchirapalli, Tiruppur, Pudukottai and Sivaganga.

The Situation

The consortium of HIV Positive Women’s Networks worked for 6 years supporting the Indian government’s programme to prevent HIV transmission from mother to child. The results were impressive, out of 364 pregnancies followed up, only five children were born with HIV. The generation before were not so lucky, but they were able to live with HIV thanks to medication. Our studies show that this last generation of children living with HIV are under-served. They need counselling and support to cope with the medical, social and psychological impact of HIV combined with all the usual teenage concerns.
Eighty percent of children living with HIV are now adolescents. Many children are traumatised by the loss of one or both parents to HIV/AIDS and by the knowledge that they carry a life-threatening virus. There is no proper counselling. The Indian government gives free HIV medicines but the clinics are busy and counselling is inadequate. International guidelines recommend that discussion about HIV should start by the time the child is aged eight. But guardians are reluctant to talk about their child’s HIV status and its implications, even when they are in their early teens.

The guardians, often single mothers or grandmothers, are scared of the child’s reaction and want to protect them. But it is counterproductive since most of the children know they have HIV but don’t know the full facts and become confused. Early disclosure leads to better adherence to treatment in later adolescence.

Most children living with HIV suffer discrimination and are lonely, many are misinformed and some are neglected. This can lead to psychological stress, low self-esteem, depression, discontinued education, irregular treatment and sometimes to suicidal thoughts. The older adolescents are becoming young adults. Girls marry earlier than boys and some have already married. Because there is no guidance, both boys and girls take inappropriate decisions regarding sex and marriage.
The Solution

We train volunteers and leaders from the Positive Women’s Networks. They attend busy government clinics to help out with counselling and visit children and guardians in their villages. They identify children in crisis - sick children, those who have not started or have stopped treatment and those with problems at home or school. Those in need are given bus fares to attend clinics, money for additional medicines and tests, and other support, for example school uniforms. The volunteers accompany guardians and children to clinics, schools and social welfare offices for benefits.

We run workshops for guardians and meet them individually to discuss how to counsel their wards on HIV facts, regular tablet taking, a healthy lifestyle. They are given suggestions on how to answer the most common questions –

“How did this virus get into me- when will it leave?”
“How long do I have to take tablets?”
“Who is to blame?”
“Why do I have to have all these blood tests?”

Volunteers counsel on issues of home conflict and discrimination, refer children with serious psychological or medical problems and get children back to school. Workshops are held for older adolescents to discuss puberty, sexuality, relationships, safer sex and marriage plans.

Our project guides this last generation of children living with HIV to increase their chances of growing up normally - resulting in a long and productive adult life, married and with healthy children. Priority will be given to adolescent girls and young women since they have more complex needs and some are approaching marriageable age. This generation will become role models, will not infect others and will be able to advise their peers on life with HIV and HIV prevention. In short, the project augments the other work we undertake to ensure an HIV and Aids free future.

THANK YOU FOR YOUR SUPPORT