

# CHILD MOBILISATION PROJECT

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# **INTRODUCTION:**

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## **WHAT YOU SEE IS WHAT YOU GET.**

While the will to give and to want to help is a great thing – it is open to abuse and not always through corruption, mismanagement of resources is as often a reason for money to run through an organisations fingers without any difference being made. There are countless examples that could be given to demonstrate this point and the larger agencies are as culpable of waste as any other.

The temptation to misappropriate money is not peculiar to developing countries, it is simply they do not have the rigorous lines of accountability that more sophisticated countries have put in place over the course of decades – and even those are not immune.

Furthermore, NGO's have a complicated relationship with their stakeholders and often a project panders to their desires more than catering for the needs the NGO is supposed to be serving. It is all too common a sight to see a visiting, often Western donor, being shown an immaculately run organisation without them ever gaining any real insight to the actual day to day operation. Orphanages are a striking case in point, for while the stakeholder might finance a wonderful little paradise in which the children grow up, there is often no provision for the children thereafter and it is then that a large majority of de- culturalised children enter society only to find they are stigmatised and left on the margins and subsequently are forced into crime and prostitution.

The Mobilisation Project is a grass roots project, that has been developed with a keen eye both on the actual needs of the those it addresses and on where money is being spent and where it is spent, how it is accounted for.

The key to its success is good organisation and planning. Each phase of the project has been very clearly explained so that in a country where time keeping is a loosely applied phrase, the project will not stumble. The project utilises existing infrastructures, both transport and medical, making them in turn serve the needs of the project.

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## **MEANINGFUL SUPPORT WHERE IT IS NEEDED:**

Finding the problems are not difficult – in a country with the population the size of India poverty and the concomitant problems that accompany poverty are ubiquitous. In developing any project there are a number of criteria that needed to be addressed.

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## **QUESTIONS TO ASK IN DEVELOPING A PROJECT:**

- **WHAT IS IT'S GOAL?**
- **WHAT ISSUES DOES IT ADDRESS?**
- **DOES IT CHANGE THE QUALITY OF LIFE?**
- **DOES IT PROVIDE MEANINGFUL SUPPORT?**
- **DOES IT EMPOWER OR DIS – EMPOWER?**
- **DOES IT EDUCATE?**
- **DOES IT ADVOCATE?**
- **ARE THERE ANY LONG – TERM BENEFITS?**
- **ARE THERE ANY LONG – TERM DRAW BACKS?**
- **IS THIS THE BEST WAY OF DELIVERING A SERVICE?**
- **WHAT ISSUES ARE RAISED?**
- **DOES THE CONCEPT PROVIDE A SOLUTION TO AN EXISTING PROBLEM?**
- **IS THE CONCEPT RELEVANT ON A GRASS ROOTS LEVEL?**
- **IS THE CONCEPT SENSITIVE TO THE CULTURE IT INTENDS TO SERVE?**
- **CAN THE PROJECT'S SUCCESS BE MEASURED?**

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## **INTRODUCING THE REGION:**

Andhra Pradesh is situated in the central East area of the sub – continent of India. The state capital is Hyderabad. The population of the state is 76,210,007 as per the 2001 census. The land area 27,5069 sq. kms, roughly comparable to that of the United Kingdom.

The Nellore District of Andhra Pradesh has a population of 2,668,564. It is made up of forty six mandals, which are sub – divisions of the main district. Each mandal oversees a number of villages. The total amount of villages, both scheduled cast and unscheduled cast, which include tribal villages, made up of fisherman and other such local tribes is 1,124. The majority of the population live in rural areas and work in the agricultural sector.

## **1/ THE ORIGIN OF H.I.V. INFECTION IN THE NELLORE DISTRICT:**

Look at any map of the district and one feature of the region becomes immediately apparent: the National Highway. The road runs from Kolkata in the North, fifteen hundred kilometres away, South through the district, to Chennai a hundred and twenty kilometres from Nellore town, the district’s centre.

All along the highway there are road side restaurants and “dhabas” (brothels), where the thousands of truck drivers who use the highway everyday stop. They routinely practise unprotected sex with the prostitutes, who had become H.I.V positive. These same drivers return to their villages, perhaps after months of absence and carry the infection into their local communities.

The National Highway represents the main thoroughfare through which H.I.V has been filtered into the intricate web of village life throughout India. Andhra Pradesh, and the Nellore District in particular, has a higher infection rate than many other areas of India and it is clear now where the reason lay.

What emerged through research was that not only did the Government District Aids Office not have up to date records of child infections, the local government hospital had a very low record of child infections on their registrar. This information did not tally with information gathered from the field which revealed a significant number of infected children.

For while the ART clinic in Nellore had only ten children registered, and the District Health department had no separate figures for child infections, information gathered through a local positive network revealed eighty one names in only six mandals of the forty six in the district.

If the mandals from which records have been gathered reflect a general trend then the likely infection rate in the Nellore District will be in the region of six hundred cases.

Visits to children in the field revealed that many of them and their carers, usually a single parent, most often an H.I.V. positive mother or a father, or if both parents were dead a grandparent, had no idea that there was a need to monitor their infection. There was general ignorance concerning the presence of an ART centre at the Nellore Government hospital and an equally widespread ignorance that it was necessary, following a positive diagnosis, to be CD4 tested.

The government ART clinic does issue free first phase Anti Retroviral Treatment. At present, the government of India does not supply second round drugs due to their prohibitive cost, but there are signs that this might change.

ART does prolong life and return it to one of relative normality. It is prescribed in India when the cell count reaches below 250. The current recommendation in the United States is to begin Anti Retroviral treatment when the cell count reaches 350.

Many of those who had tested positive had experienced little counselling and no support and were left, once diagnosed, to return to their villages, feeling frightened and isolated and afraid they would die. Many children have witnessed the death of a parent,

some have lost both parents. The mother's have seen their husbands die and often from tuberculosis, the most common fatal opportunistic infection in India.

Despite these harrowing experiences, many have to live in secrecy. The children hide their infection for fear of being ostracised and expelled from their school and alienated by other children.

The adults live in secrecy for fear of losing what employment they might have. There are many cases when even the families of infected women and children reject them, forcing them to leave all that they know and seek shelter and work in an unknown slum area.

Without work, and living on government rations, the women and the children were severely undernourished. Their diet was one of subsistence only. They ate rice three times a day, would have an occasional vegetable in their samba (gravy) and little else. There was never any milk, fruit or egg in the child's or carer's diet.

Anti Retroviral drugs are an aggressive drug and require to be supported by a good diet. Women had stopped their treatment because they were not eating well enough to support their medication which made them sick if they took it while hungry. In this they were caught in a cycle of ill – health only because of poverty.

A study was carried out among HIV positive women with one or more child that looked at the eating habits of the household and what they could afford on the money they earned from part – time jobs and government rations. (See Appendix One). The results of the study clearly revealed that in cases of extreme poverty the food stuffs that could no longer be afforded were milk, eggs and fruit of any kind. These items contain significant nutritional benefits to a child, especially in a vegetarian diet, where these foodstuffs are the only source of good fat and thus energy which in turn boosts both the growth and weight of the child and its immunity system.

Most children encountered in the research were under weight and under nourished. Their immunity systems were thus working below their optimum levels and thus opportunistic infections were more prevalent in children, who are already susceptible, as all children's immunity systems are vulnerable.

**To try and find a way to elongate and improve the quality of life for children with H.I.V/ Aids, in the Nellore District.**

Although HIV is difficult to predict there are ways in which a child's health and well – being can be monitored and boosted. While, many children and their carers had tested positive there was often little follow up. Often the carer did not know what to do about their condition or how to address it. The government hospitals had not provided any meaningful counselling and there was little effective dissemination of information.

It was clear that the children needed to be CD4 tested to see if they needed to be receiving ART treatment and to monitor their cell count, which in children is more susceptible to change than in adults.

It was also clear that many of the children were not receiving an effective diet. It is generally accepted that children with H.I.V need to eat a well – balanced nutritious diet to ensure a healthy immunity system. Poor diet not only stunts growth but heightens their susceptibility to opportunistic infections, infections which all children are prone to but which HIV children are in greater danger of suffering from.

The strategy was therefore determined by these criteria and the strategy articulated:

**To get HIV positive children in the Nellore District CD4 tested and have their health regularly monitored and to provide vital nutritional support to boost the children's immunity systems to better equip them to fight the virus.**

The strategy was broken down into systematic segments in order to attain the goal:

- 1/ Establish contact with the government hospital and work alongside them to ensure they could accommodate those children we brought to them and to ensure the children received proper medical attention and accurate information, where previously they were treated badly.
- 2/ To set the number of children we would target in the first year.
- 3/ To compile an accurate list of children and to compile a schedule to accommodate the three visits each child would be required to make to the hospital in the first month over a period of three weeks, (1<sup>st</sup> visit: registration at the government hospital, 2<sup>nd</sup> visit, CD4 test, 3<sup>rd</sup> visit: CD4 results). And to ensure that all follow up visits were accurately scheduled.
- 4/ To provide transport to and from the hospital to enable the children and their carer attend their hospital appointments.
- 5/ To appoint two field operatives to maintain effective contact with the children, often living in isolated areas, to ensure the appointments are kept.
- 6/ To provide nutritional support, the contents of which being determined from the focus group meetings and from medical experts working in the field of H.I.V.
- 7/To cost the nutrition pack in such a way that the best nutrition might be achieved within the affordable constraints.
- 8/ To establish accounts at village shops for each child so that they are able to receive fresh produce through the month.
- 9/ To ensure that all stages of the process are accurately monitored for transparency and to maintain accurate accounting practices.

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**KEY PERFORMANCE INDICATORS:**

- Number of children targeted.
- The number of children registered at the Government Hospital.
- Number of children CD4 counted.
- Number of children placed on ART.
- Number of children whose diet improved.
- Noticeable improvement in their health?
- Days of sickness.
- Did the child's cell count increase?
- Did the weight of the child increase over the course of the year?

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**SUB – OBJECTIVES:**

- Carers included in the monitoring project.
- Information regarding nutritional food stuffs was provided.
- Established network of HIV positive children and carers.
- Addressed stigma.
- Enabled advocacy of sexual health and prevention.
- Advocacy of HIV health care.
- Provided support of marginalised individuals.
- Developed a support network for HIV positive women.
- Built trust within the HIV community by being supportive and effective.

During a meeting of HIV positive mothers and their children a survey was conducted in which a number of questions were asked about the diet of the children. This information was collated and then compared with a small group of women who were asked similar questions but who went into elaborate detail with regards their monthly expenditure on food.

There was virtually no difference in the make up of the diet from one mother to the next. Their incomes ranged from 500 rupees a month, (£6. 22) to 1500 rupees a month, (£18.80). Despite, this variance in income level they all ranked at the lowest end of the income group and all their diets were the same.

Rice made up the principle item in most of their meals – each person consuming in the region of 10kgs of rice per person per month. (See appendix for full details).

The information from the survey indicated that they provided some milk, and eggs and fruit when there were funds enough to provide them. The main bulk of the diet was made up from dry goods: rice, dahl, lentils and pulses.

It became clear that it would be pointless to provide additional dry goods to the women as they already managed to afford these items as their basic foodstuffs, which all Indians eat as a matter of course.

Although the balance of their diet concentrated too heavily on rice, it was not practical to address this cultural point as there would be no likelihood of a change in this practice.

During the in – depth discussions with a small group of women it emerged that in fact the children were almost never given milk or eggs or fruit.

Following a detailed analysis of their food intake and their monthly income, (see appendix), a clear picture emerged with regards their actual practices.

It became clear that the best option for a nutrition pack would be for it to contain these rich, fresh foodstuffs that contained natural fats, proteins and carbohydrates as well as a multitude of vitamins and minerals. The combination of which would provide a significant boost to their meagre diet

### **MOBILISATION:**

In simple terms the children needed to be taken to the hospital. The obvious solution to a Western eye would be to provide the required transportation which would pick the children up and take them to the hospital and return them.

Aside from the mothers being overlooked in this scenario who are in as much need of a such a programme as the children, what mitigated against this approach being successful was the geography.

Nellore District is a rural area made up of over a thousand villages. It would be impossible for a bus to reach all these areas, not only because the roads are often only dirt tracks, but because it would take too much time.

The cost of a bus and a driver as well as the running costs of a bus were looked at and then compared to what it would cost if each carer was responsible for bringing the child to the hospital themselves. To ensure that each child was monitored and that they

kept to their appointments, the cost of two field workers was included in the budget.

It emerged through the calculations that by avoiding the cost of a bus, the most obvious route, the running costs would be at least 75% less per month.

Furthermore, by encouraging the carers to attend hospital with their children they were included in the scheme and in the process could begin to form a network of their own. The carers and children alike would in due course benefit from these regular encounters in many ways which are discussed later.

An average of forty rupees per return journey for carer and child was budgeted which catered for a range of distances and represents a mean figure. This sum is distributed to each carer on presentation of a valid bus ticket, for which they sign in a registrar.

(See appendix two for a full breakdown of transport costs.)

### **NUTRITION:**

Following a study of the eating habits of impoverished households and following advice from three doctors who specialise in H.I.V. the contents of the nutrition pack were determined based on the financial constraints that determined how much could be spent on each pack and what could be afforded that would constitute a meaningful and in some part measurable difference to their existing diet.

Milk, eggs and bananas were recommended as important staples for a growing child who is fed a vegetarian diet. Each of the food groups offers significant nutritional value. They should over the course of time when taken regularly, boost weight and growth, and boost the body's immunity system and bring it up to normal levels, equipping it to better fight the virus.

Given the precarious nature of H.I.V there are no guarantees that the nutrition packs alone will sustain life and health. However, it is clear that a healthy diet plays a key role.

To ensure that each child received its pack and that the foodstuffs were fresh it was decided that accounts with local shop keepers would be opened in the villages on behalf of the children.

Although the food items were 15% more expensive when purchased through the local shops rather than through a central wholesaler, the effective distribution of the fresh goods remained problematic and would entail further costs of transport and distribution.

Account books were issued to the children in which the store keeper would record the foodstuffs consumed, up to the allocated sum per month. The store keeper would sign off on each purchase in the book.

The book in turn is monitored by the project liaison officers who ensure that the store keepers are paid and that there is no abuse of the system.

The cost of each nutrition pack from a village storekeeper comes to 226 IDN RPS a month and is broken down:

|                           | IDN RPS. |
|---------------------------|----------|
| Per egg 2.20 x 30         | = 66     |
| Per banana 2.50 x30       | = 75     |
| Per ½ litre milk 10 x 7.5 | = 75     |
| Milk biscuits pkt x2      | = 10     |
| Total                     | = 226    |
| @ 76 rupees to U.K pound: | = £2.97  |

### **NUTRITION TRAINING:**

In addition to providing valued nutrition to the children, their carers were given some basic training in food nutrition. They were shown how to prepare certain foodstuffs that are locally available that provide good nutrition, namely green leaf vegetables and ragi (malt), belam (jaggery). The inclusion of these affordable items into their diet not only boosted their diet but empowered the women and gave them some sense of control over the virus which has positive psychological effects.

To ensure transparency at all levels, clear lines of accountability were drawn. At no point, was any single person in a position to abuse the allocation of funds. The Project Liaison Officers are required to keep an accurate record of all travel cost disbursements. The store keepers are required to keep an accurate account of their transactions which are signed against on behalf of the recipient. The Project Liaison Officers monitor the store keepers who are in turn overseen by senior staff of both the local NGO and the lead agency involved in the project.

To further ensure clear lines of accountability it is recommended that the local NGO is not left in sole charge of administering and accounting for the project. To avoid any suspicions arising and to ensure a high level of transparency it is suggested that a lead agency be used to monitor the quarterly allocation of funds and to check the accounts for each period.

The mobilisation project goes some way to meeting the needs of the children, but it only goes so far. There are gaps that quickly become apparent: While, there are government hospitals they are lacklustre in their care, poorly staffed, under – funded, often unhygienic, and not places anyone wants to be. Even the poorest people will go to a private hospital rather than to a government hospital for treatment and though they will be charged and not necessarily receive any better medical care they come away with a feeling their needs have been attended to which is never their experience from a government hospital. There are countless stories of patients being mistreated and neglected.

### **MEDICAL CARE:**

There are no funds within the mobilisation project allocated to medical supervision. How to allocate those funds would be difficult and would have to be done on a case by case basis and granted only in life threatening situations.

There is also the issue of medicines for opportunistic infections which can range from minor skin dermatitis to tuberculosis and meningitis, which is very expensive to treat. There is no government subsidy for these medications and there is no international agency presence in the region that might be able to make this provision.

### **ORPHANS:**

The real figure is only beginning to emerge. Over the course of time an accurate picture will emerge through the network formed by the mobilisation project. What is key to developing a relevant response to children orphaned by H.I.V. in India, is to try wherever possible to keep the child within the network of the wider family. It becomes more problematic in cases where the child is H.I.V positive as no one then wants to look after the child.

**MEASURE FOR MEASURE.**

There is an ongoing dichotomy in any kind of humanitarian endeavour wherein what is given is required to be seen to have had a measurable impact. On the one hand it is hard to scale need and on the other, how can one measure happiness, or misery? The spectrum of poverty is vast – ranging from those people who are literally starving, to the half – starved and malnourished who live in slums and scratch a living from man’s detritus, to the better fed, but infected and diseased. In amongst all this suffering is it relevant to attempt to qualify the need?

*“A measure of success is always to see the knowledge of a particular subject or skill being translated into practice.”*

How can a project be judged a success when all that has happened is that children have been taken to hospital and given some additional food? We cannot say they would be dead if the project had not reached them and yet in some cases this is almost certainly true. The success of the project is not therefore something that can be easily measured but if the parts of a thing make up a whole then what might be observed is a significant shift from a place of confusion, ignorance, fear and isolation to a place of some security, a little comfort in the knowledge there is someone on the end of a phone and some peace in the knowledge that at least their children will be guaranteed good food for as long as it lasts.

Desperate poverty cripples the spirit and the body - the provision of some hope cannot be measured in terms of statistics but can be seen in how their lives regain some level of security.