

SAKINA KI BIMARI

"Sakina's illness" and other stories

Weaving a tapestry	2
Asma decided to have an abortion and a tubectomy.....	11
Safeeda and Babu:	15
Khodeja and Mairun:	18
Self Medications: "Dear Dr. Gazadar" and her magical medication.....	22
Rehmat and her son who had scabies.....	25
Our own immunization campaign 1980-83:.....	27

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Weaving a tapestry

These stories were written in August 1984. Many of us who founded SPARC worked in a community centre at that time.. Several of our friends came as volunteers and as a result there was a range of skills and human resources available to those of us working at the centre. We worked together for several years where we experienced the most powerful experiences which have shaped our practice subsequently. We all finally left that centre because its institutional structure limited what we believed to be the role that NGO's needed to play. These stories were our personal farewell to the several years when we interacted with many poor communities and women. Through these stories we recall some of the most powerful experiences we shared with women there... most of who now form the core group of Mahila Milan.

As a group of community workers who gradually developed insight into and respected the process by which women learn, we used these insights in our work with groups of women in urban settlements of the poor. The most valuable lesson we learnt was that each individual/group knows what is best for them - they don't need to be taught - what everyone needs is to know of options available and how to reach them.

These are OUR stories. They are written by some of us and are, based on our perceptions. However, the experiences belong to the women... those whose experiences initiated this process, and later the collectives who listened to these stories, participated in them and made them the collectives "resource". Most of us, at that time were unable to explain what was happening. We all knew that a typical health program, a traditional welfare centre was going through an upheaval. Everything was changing, and being part of that change, we were too caught up in what was happening to analyse it.

There are a few selected stories in this publication. Every woman, every worker had several stories which were their favourites... stories which they would start narrating given an opportunity... a process which this newly evolving process intuitively supported. Clearly it was the most effective communication between all of us. It made us laugh, often at ourselves, it gave us insights, most important we all believed in these stories... because they were OURS. Not some propaganda about what is good to do.. something poor women are sick of hearing, but rarely tell anyone.

This process was not invented by anyone. In fact it has always been the most routine and traditional method by which women talk to each other. Stories have a special place in women's lives... they reflect the manner in which women are socialised from childhood from where they derive their imaginations about what they should aspire to be.

We used the form, but changed the content. Rather than further enhance the sacrificial and "sati savitri" imaginations, we replaced them with events in which all or some of us participated, wherein we felt some sense of personal or collective achievement. Rather than confront those traditional stereo types, we subtly began to replace them with NEW

alternatives. Just as the original stories never directly forced women to accept their "moral", so the new stories and their messages did not demand acceptance.

These stories focus on issues of health. There are similar stories related to other areas of their lives. These stories were originally written up to be part of another publication on non formal education strategies in health which was published by PRIA (Delhi).

We have revived these stories again to serve several purposes:

1. To illustrate processes by which a group or federation can first support individuals and groups to achieve what they need, and through the communication network, absorb the learning, the achievements and the insights into its larger work thereby allowing those processes to be useful to others.
2. Women and their survival strategies form the foundation of how poor communities subsist in the cities. Yet most processes rarely touch on their needs, their recourses and even worse, rarely build up women's capabilities to deal with those processes. What we began in 1980 when this kind of work evolved, forms the basis of how SPARC integrates women, their learning and insights into its work.
3. Each story further tells many stories... we hope the reader will delve into these and think of the issues in learning, in problem solving and sharing that they unfold. It is time that everyone paid a lot of attention to ways in which women teach and learn and hopefully we can create mechanism by which women participate in the development and change process rather than become objects and consumers of that process.
4. Finally, this kind of material is precious because it is our history. Rarely do community activists have the honor or the privilege of working with the same people for 15 years, and even more rare is the opportunity available for them to link what they do today with what they did with those women many years ago.

SPARC has that privilege. Most of the women in those collective now form the core leadership of Mahila Milan. We continue to tell stories, and in many instances major organizational strategies have emerged from such events and stories. To illustrate just one, there is the story of our first immunization campaign. In 1990, we undertook a mass immunization campaign for measles for the Bombay Municipal Corporation (Attached as annex A). To others it was a FIRST. To us it was an expansion of a process we had begun 10 years ago.

Before we move to the stories, we will briefly describe the institutional set up within which we worked, the manner in which we formed these groups and the context of the health program.

Setting up the process: The Community center is located in the crowded and inner parts of central Bombay. It is an old and established community center, established in 1926 by American Missionaries in the tradition of Neighborhood Centers in the USA. The center

provided a wide range of programs which included a comprehensive health center, day care for babies, a nursery school, various classes in stitching and typing, counseling centers and so on. IN 1979, sponsorship of poor children was initiated whereby monetary assistance was given to children from the poorest homes in the area. All the women who formed part of this process first came together under the aegis of that sponsorship program.

These women were mainly heads of their households (i.e. they were widows, deserted women with children or women with husbands, who were either not working or incapacitated) and in routine circumstances would have interacted with the project to take the money, reply to the sponsors letters and to utilize any services which the center would provide them. Not content with this kind of arrangement, these 600 women were organized into 7 groups. Each group comprised of women from a particular geographic area. They were to meet once a month for a period of one hour to an hour and a half.

This formulation was initiated under vague feelings that such collectivity would promote solidarity amongst the women, that those of us who were administering the program were not content to just efficiently transact monetary processes. But there was no idea or plan in anyone's mind of what exactly would occur in those sessions. We therefore translated these concerns into two main objectives for ourselves. Firstly, to help women from each area to operate as a collective, and to be supportive of each other at times of crisis. Secondly, to evolve through their own experiences, a meaningful learning experience which over a period of time would become a meaningful alternative which helped face daily crisis and other situations in life more effectively.

Health was an area on which we frequently dwelt on. It was suggested that we start volunteers training program. Infact, given the popularity of training programs in health evolved by various groups in the city, we were very seriously considering this possibility. However, we decided against it for two reasons. We were of the opinion that such a model was relevant in areas where there were no doctors and hospitals (e.g. rural areas). In Bombay there were enough basic facilities. What was needed was an orientation to use these. So whatever basic health education was necessary we felt should be given to all. Secondly, most of the health workers were given some monetary compensation for the work they were doing. That in fact, seemed to carry its own implications and a host of problems rather than advantages.

For instance, although this was seen as an honorarium, workers saw it was a "wage." This made them identify with the agency rather than with the community. Besides, given the financial problems which voluntary organizations face perpetually it seemed to be asking for trouble to initiate a program and know from the start that you could never pay minimum wages.

Finally, there was serious misgiving about sharing any knowledge with a few from the larger group. Often the difference in knowledge levels initiates the process of exploitation. For instance, it has been a common event in our neighborhood slums, that whenever somebody needs immediate hospitalization, the "dalal" (agent) or some intermediary who has knowledge of how to use the hospital will do so for a fee. It could well be that by training a

few; we were possibly creating a new batch of "exploiters", when in fact our intention was just the opposite. However, we did have a group of about 20 women and a series of young persons who were all called volunteers who met initially twice a week, and gradually once a week, and later met whenever the need arose. These groups fulfilled dual function. They were women who were very excited with what was happening in the groups, had tried to utilize this in their lives. They found it effective and were keen to learn more. Most of them were either already leaders, others were potential leaders.

We utilized this enthusiasm to give them knowledge that they were keen to acquire, but also, sought something in return. There was an unstated demand that each person who was "assisted" would then assist the next person in need. Often the initial process was uncomfortable to women, but we sought to support them in that role rather than help the next person reach the service. Initially women hesitantly began to help other women in their own areas, but gradually began to revel in their expertise and assist others from the "outside".

This gave us an inkling of how we could get all six groups together. They also shared weekly events which occurred in their slums. This provided us many live instances to evaluate and analyze, and to become sensitive to the type of problems they faced and how they resolved it. They were encouraged to discuss their own problems, and that of others as well as. Often women would go back to their settlement, talk to the other women, and seek group assistance to solve some problems.

As a result, although they were not trained as leaders, or health workers, they would collectively take on that role, and the entire experience centered around sharing new knowledge rather than just gaining knowledge. Much of the weekly conversation was also to evolve a variety of strategies for communication. Knowing that this was vital, women from the collectives became partners to the workers in the organizations in closing the gap of communication. It soon became clear that their levels of communication were more efficient than that of the worker.

In this manner, gradually they also took over the role of leadership at the weekly meeting. Often we would have spent part of the month assisting a particular woman with her problem, and would draw upon her to relate this experience. Since this experience was live, and the woman known to them, interest and absorption of knowledge was greater.

Almost every woman who attended the process had a story to tell. The ones included in this case study are those, which are every one considered the most effective, and which were retold the most. It is also true that every woman did not succeed in everything she took on or that each benefited to the same degree. But the confidence to deal with the traumas was palpably present.

SAKINA KI BIMARI:

Sakina is the grand old lady from the Central Railway Zhopadpatt. She is a widow with two sons and several grandchildren. She and as a well loved woman, known for being very favorable to her daughters-in-law. Both the staff and the members of the group had labeled Sakina as a hypochondriac. She had a dramatic manner of proclaiming that she was ill after which she would proceed to describe in great detail, all her symptoms and then claim that she could not be cured by any doctor.

In order to understand what was wrong with her, we sent her first to our medical center. The doctor stated that since she had several symptoms and some chest inflammation as well as signs of TB, we should get her chest screened. And therein began her saga. Veena, who was then a volunteer and who was assigned the job of assisting patients who needed an "escort" for the first time, went along with her to the Foras Road TB Clinic. Veena could barely restrain her temper because Sakina proceeded to tell all the doctors at Foras Road TB Clinic that there was nothing they could do to make her feel better. All the doctors had tried their best to get her history, but all they heard was her own diagnosis.

Due to Veena's insistence that they should ignore Sakina and her talk, the doctor felt that she should first take a course of antibiotics so that other inflammations could be ruled out. Sakina had to take 4 large colorful capsules a day for a week.

Then she had to go back to the clinic, at which time all other investigations could be made. But a fortnight elapsed, and Sakina never went. Veena went there with another patient, and the doctor inquired with Veena about Sakina's whereabouts. In her enthusiasm, and exhilarated that the doctors were gradually increasing their involvement in this process, Veena rushed to Sakina's house and found that Sakina had no intentions of going back to the clinic.

There was a head on collision between the two stubborn, strongly-willed women and Veena stormed out, came back to the clinic stating she would have nothing to do with Sakina in the future. She felt upset that Sakina felt no sense of obligation or gratitude for all the care and concern that was being showered on her. She felt that Sakina was a good example of why the doctors did not care for the poor patients.

In an unusual moment of inspiration, there was an impromptu meeting of all the persons who were there to share their views on what had just occurred. Most of the people present shared Veena's views and would have liked her to wash her hands off her. However, some of us began to play the devils' advocate, and began to defend Sakina. It began like a game. But as we got deeper into it, what we were discussing began to sound viable.

May be, it was argued, she is frightened, and was using this big talk as a bravado. Or may be, by always complaining, she kept getting attention, something she needed more than the cure. May be for us this is trivial, but it is important to her. We already had enough experience sharing, in which we saw that unless a woman was very ill, neither she herself nor the family

paid any attention to her or sought medical assistance. Often, stress manifested itself in the form of psychosomatic illnesses, and we wanted to acknowledge that for it by providing women some space to seek help. It was not the most effective or positive method of seeking attention, nevertheless, we also knew the circumstances, which led to this.

Any way, after some hectic discussion, we were all ready to accept that Sakina may have reasons to behave like this which at the moment we must accept, but we also needed to know how we could help her to overcome it. While we were not sure whether or not she had TB, we felt that somehow this would be an important milestone in our women's groups. In a way, in her exaggerated manner, Sakina had crystallized the problems, which most women show. We knew we were on the brink of something, but we had no idea of the fantastic breakthrough this was to offer.

Sakina's group meeting was to take place the following week. At the meeting, we used TB detection and the usage of the facilities at the TB clinic as a new topic. There was a role-play done by the volunteers, and much time was spent on relating the experiences of the women's reactions to TB. How women tended to hide that they or that any one in their family had TB. - How often, the doctors did not tell patients that it was TB and as a result, despite the patient taking treatment, the family did not know the seriousness of the illness and the necessity of the treatment.

We went into a detailed analysis of why there is a stigma, why people hid the fact that certain diseases are prevalent in their homes and we shared the statistics of the Wards(Municipal District) with them. Everyone listened but did not react. Then as if it was a very routine question, we asked Sakina whether she had gone back to the TB clinic to see the doctor. She was stunned that we should ask her this question in front of the group. When she tried to change the topic, we made a bold statement to the effect, that while we admired her for being one of the first to actually go to the clinic, we were disappointed with her because she had not gone back. Infact, we were all concerned that she had not and wanted to know the reason why.

We all continued in this vein for some time, re-emphasizing that she was a brave and a very smart woman who was investigating by herself what was the cause of all her problems. Besides, we said since she was a well-admired woman in her slum, her undertaking this venture would set an example to the rest of the community. Her going for investigation did not necessarily mean that she had TB. Besides even if it is TB, was it not better to know that. Was it not better to treat it rather than to ignore it until it would kill her, because it would not only kill her, but it would also infect all her family and neighbors. Poor Sakina, with every positive stroke that she got, and with every admiring glance that she got from the women, she was pushed into a corner. We had gambled on her forthright nature and her decisiveness.

Once having decided that she would, after all, concede and participate, and become the "heroine" of the day, she also decided to hog the limelight, and dramatically, took out all the antibiotics and flung them on the "chattai" (the straw mat on which we sat), saying that she could not swallow them because they were TOO LARGE.

The next 15 minutes were unbelievably enlightening, funny, and so very dramatic, that in themselves they provided so many lessons. They not only electrified the group, but in later sessions, have never failed to have the effect as we anticipated.

She proceeded to state that she had gone to several doctors and in fact, by the time she finished, she had mentioned every well known private practitioner in the areas. But, she said, she was disgusted that none of them could give her the kind of medicine she wanted. She did not like injections, they poked - she did not like pills or tablets because she had trouble swallowing them, she did not like liquids because they tasted vile. Why are there no other kinds of medications? She had the women spell-bound and very sympathetic. If we were not careful, this would rebound on us. So very dramatically, we suggestedthat maybe what Sakina needed was a "soonghanenki dawa"..., medication which she could inhale... In this vein, it continued, all of us were in splits of laughter thinking up pleasant ways in which we could take medication which then would not be unpleasant.

Then every one sobered down. When we came back to the reality. We discussed.... Illnesses were not a joy ride, none of us fell ill out of choice, and often, despite all our efforts, our loved ones fell ill. Unlike earlier days, when one could not have access to medications, there was some improvement now. We could at least feel confident now that we understood what the cause was and what had to be done. We also knew that the methods the doctors use were alien and often frighten us. Was running away the only answer? Making excuses in the start was Ok, but even that meant wastage of precious time. How were we as a group going to deal with this problem. Were we going to make excuses, or make them listen to each other? or were we going to be supportive and help face fears and resolve it?

We added another dimension to this matter. Veena was sufficiently calm to relate how she felt about this matter, and how she had initially evaluated Sakina's behavior, and how let down she felt. That she had not wanted to have anything to do with Sakina. This became the basis of indicating to the women, that they were also responsible to come halfway when someone agreed to help them, and to treat this as an equal relationship. After all, unless it was meaningful to both, this could not be sustained.

Subsequently, Sakina completed her course, and also underwent the investigation to find that she did indeed have TB. Instead of not taking medicines, now, she would come and grumble, complain, discuss this treatment. Since we were all involved in this strategy, and we all wanted to see Sakina through this trial, whoever was present listened to her tales. Besides she knew how to keep an audience involved. While these discussions were on, we began to read as much about TB and learn about it from doctors and discuss it when Sakina was around. She would actively participate in the discussions, and seek explanations. Some instances like "drug resistance." Why does it occur... what are the reasons, or, we would talk of the various detection symptoms and so on.

As expected Sakina began to talk about all that occurred at the Center in the community. She would have a couple of people from her slum, tagging along with her, sheepishly stating that they were going for a check-up. Initially, Sakina wanted an "escort", but gradually,

she relented to taking a referral note, and soon was confident even without it. It seemed that we had been fairly successful in the messages we transmitted, and because Sakina was tough. She would not take anyone who would not undergo treatment if found ill. Once she even went to the extent of getting a very ill person from Matunga, stating that he was not taking medication. She felt that he needed to be hospitalized, and she knew we would help firstly to convince him that he should go to the hospital, and secondly to admit him if he agreed.

Sakina was a priceless investment. Right in front of his family and all the others who were around, she gave him a near replica of the treatment the group had meted out to her at that first meeting! She proceeded to draw for him a picture of what would happen in the future, how he was going to infect every one, and how he was finally going to die! No small wonder, at the end, he begged to be taken to hospital.

This provided us with the contents for our women's meetings for the next three months. Whenever Sakina could come, she related her experiences herself. There were others who were also going through the same process and they too assisted in the process of educating the rest of the group. Gradually, each women's' group took on a commitment to first of all, take their own family for a TB check-up by going to the clinic, then, to assist in the motivation of at least 5 families in the vicinity. All those who had already gone to the community would volunteer to take their neighbors for the first time, and several others volunteered to come at least once a week to take any one who wanted to visit the clinic.

As a result, we evolved several small details to make this strategy work. For instance, we worked out that if the people were prepared in advance about what to expect, it was easy. They could complete all investigation when they go with their early morning sputum in air tight bottles. Then they needed to go again at 9.00am, the x-ray would be collected on the third day, and so on. All these things were repeated on and on, and all those who had TB had to get all their neighbors motivated to check out their health. This serves a very valuable function. It not only fulfilled preventive functions of screening the neighbors, but since the patient was assisting in this, there was reduced stigma. Patients and the community were now aware that once the treatment was established, the patient would not transmit the illness.

Much later, we also got the government to agree to allow us to become a sub center and after the initial detection and establishment of the regimen was done, the clinic would give us the medications to give out. We also made a slide show of Sakina talking about her experience with TB, and just a few months later, we began a campaign of checking all children under five by doing a Montoux' test. With the awareness about TB, and the readiness with which they accepted this program, we were able to set up a schedule whereby the doctor and other volunteers would go to any slum, and administer the test with the help of the women from each area who came to us for meetings.

The local women would gather all the children. Once the test was administered, they would be told how to check if it was positive, and to bring the child to the clinic to show to the doctor. Since the indication was a swelling, this was easy, and many children were detected

at an early stage. This led to screening of the whole family again, and starting of the drugs. All women from the community were now taught about TB by those who came to the Center. Infact they were encouraged to bring them along if any questions were left unanswered. This led to many others joining the groups and attending meetings.

We have had many instances of people going to the village, taking drugs with them and also, taking a letter from the doctor about their illness, and seeking information in the village about how treatment can be sought there. They claim to have taught their families about the symptoms, and often accompanied them to the district hospitals, where they claim they talked of how well Bombay hospitals treat the poor, as a means to get similar service!.

Asma decided to have an abortion and a tubectomy

Asma has been staying outside the community center for several years. She had the most smiling disposition when relating to people on the street and for a long time (about two years), she would chat with various community workers. When groups were formed, she did not know of this as none of the women from her particular pavement came. We began to relate to her when she became noticeably pregnant, asking her whether she had registered in the hospital. She seemed very puzzled about it. She said that she did not know anything about hospitals and registration.

So we suggested that she come to the clinic and get a check up and maybe she would get some nurse to take her to the hospital. As a result, our relationship developed - very slowly. In the beginning, it created several problems. For instance, she was very theatrical and on the basis of the fact that she considered herself our friend, she would prance into the medical department and demand immediate attention.

While we perceived her proprietorial behavior as a shield or a cover for her feelings of fear and inadequacy and allowed her to relate in that manner, the medical staff, at least initially, resented this behavior. There were many scenes and often, though she was in the wrong, she would get away with it. Anyway, she was registered in the hospital. But finally, when she was ready to deliver, there was a hospital strike and Asma gave birth in extremely traumatic circumstances, in heavy rain with help from her neighbor and her 10 year old daughter - Asma's daughter from her first marriage who she had brought along with her from Bihar.

When Asma had come into Bombay, she had started working as a maid. Another lady, also from Bihar, had advised her to get married again and even suggested the name of the man. It seemed that this man was younger than her, had a wife in the village who did not come to Bombay and hence, Asma was the second wife. This man treated her carelessly, and on that particular day, he did not come to help her. In fact, for the first year after the baby was born, Asma had to fend for herself and her two children, totally alone and as a result, this child became the center of her existence.

Her older daughter who had always trailed behind her as she went from house to house, was now to stay in one of the houses as a live in maid. Although they gave her no money, she lived there and her food and clothes were taken care of - this was Asma's way of removing her young daughter from the pavement and keeping her "safe". Seeing the struggle she had with her baby and her work, we suggested that she put her baby daughter in the crèche to keep her safe. This would be better than being on the street or with her neighbor. Asma agreed. However, within a week of joining the crèche, Asma began to fight with the crèche workers and removed her child. Two weeks later, she wanted to admit her again.

Meanwhile, other children had been admitted and there was no place for her child. So, every week she would come and chat with us. As a result, she began to meet the other women, to attend the meetings and with her extrovert nature, she soon began to interact with others and absorb many of the happenings in the meetings. Over a period of time, we all became familiar with her complicated relationship with her husband. He was almost like her third child. She would feel hurt when he deserted her. When he took money from her to gamble, she would rant and rave and throw him out of the house but invite him back after a few days.

None of us understood this behavior but we accepted it. We would argue with her, other women would try to tell her that she did not need this relationship, but she always had ready explanations and continued to behave in the same way. She also began to bring in her friends from her pavement...they began to come quite often and we noticed the gradual change in all these other women. But Asma did not change.....or so we thought.

At one meeting, we were discussing the phenomenon whereby women, after resenting the way they were treated with lesser priority than the boys in the family, proceeded to do the same in their adult life. Women shared various examples of this attitude and there was a lively discussion about how women had to have as many girls as were chanced to be born before they got the SON. Since we had already discussed the modern city culture and its effect on the sons who never look after their parents, women, at least in the discussion, agreed that it was better to nurture daughters who at least came running to care for old parents when needed than the son who never bothered.

When we came to work the next day, Asma was waiting with a grim face. She had found out that she was pregnant. Though her husband was happy about it as he hoped for a son, Asma did not want this child. She wanted to know where she could go for an abortion. We were a little worried - we did not want her to get carried away by the group discussions and decide on something she might later regret. So, instead we asked her to finish her work and come back in the afternoon. When she came back, there were several women who were there for other work, so we all gathered together and asked Asma to explain why she wanted to have an abortion.

She said that she had just lived through two harrowing years of the birth of her baby and trying to cope with her work at the same time. She felt that things were getting better now - she was feeling healthier and her baby was growing well and she did not want to go through it again. Her husband, she dismissed as only wanting to prove his manhood by hoping for a son but as usual, at her cost. She had two daughters and she did not want any more children. Her husband could decide whether he wanted to live with her or not. Infact, she wanted to have an operation(a tubectomy) so that she would not get pregnant again. All the women questioned her, asked her to think it over - even we did that. All of us were dazed as Asma spouted all the concepts and arguments and discussions that we had had in the past four/five meetings.

Finally, we decided that she had every right to maintain her decision. We told her to wait for a day or two. Meanwhile, the nurse, Sunanda, who was asked to find out about the

details of where Asma could go, without realizing the consequences of the information, told Asma about the clinic etc. in front of her husband...not only that, Asma's neighbor wanted to have an abortion too as she had a two month old baby and was suffering from TB herself...NOW every one knew.

Asma's husband threw a fit, he threatened to hit Sunanda, said he would kill anyone who thought they would assist Asma, and asked Sunanda to go away. Sunanda came running to us, frightened by the outburst. While we were deciding what to do, Asma strolled in, and comically, seemed to be comforting Sunanda and us stating that we should not take her husband seriously, and that tomorrow she was ready to go to the hospital. The next day, the other women at the pavement told us that Asma had a fight with her husband, he had beaten her, and then she had asked him to get out and leave the hut... which he had. Asma came up and was ready to leave. She even had her little baby with her. Sunanda and the others wanted to wait for a few days, worried that she would not be able to cope with her husband's fury, and not wanting to be party to a hasty act of bravado.

But there was no stopping Asma, she said if no one was ready to go with her, then she would go on her own. At last she was escorted to the clinic had her abortion, her tubectomy and she came back home. Being Asma, she then proceeded to talk to all the people in the area about it and earnestly spent the next three days which she had taken off from work to talk to all and sundry about her abortion, and why she did it. We too were amazed at her capacity not only to talk so much, but on such tabooed subjects, and at the same time, gave her all the support she needed emotionally, which meant listening to her talk.

What happened was that women who heard her talk, both on the pavement and at the Centre, were all secretly admiring her guts. They did not like the concept of abortion, but they also felt that it was a possible action. At this time, we introduced the concept of contraceptives, what they were, why, how and so on.

Within a month of Asma's abortion, about 10 women came quietly to seek copper T insertions, and many more for advice. What was fantastic was that this whole topic came out into the open, and from then on we were able to initiate several other such personal topics. In the meanwhile, both men and women in the pavement slum, gradually began to take Asma's side, and felt that her husband was in the wrong. Their attitudes were based both on their observations of how he had treated her, and the discussions she had conducted on the pavements. As a result, her husband who did not want to face community hostility, and who was in any case ready to come back to her, returned. He went to the dramatic end of asking her if she wanted him to rub her back or press her legs! A piece of news, Asma broadcasted to all the next day!!

Asma continues to come to the meetings, her general relationship with her husband is the same, he comes and goes, but we have found that we have changed the way that we perceive her. She is very much in control of her own life. In her own way, she has gradually begun to change many of her actions, she comes and consults the group whenever she needs help, she gets everyone exasperated with her attention seeking behavior, but her presence is invaluable to the group. She is a constant reminder to us

that knowledge is assimilated by different people in different ways, and the manner in which it is used also differs. It serves no purpose to demand compliance of a particular kind, for that in turn demands that a specific behavior pattern must change in order to help us evaluate that we have succeeded in instituting change.

Safeeda and Babu:

Safeeda is a widow. She came to Bombay about 9 years ago, with her husband, in search of medical treatment because she could have no children. After a year's stay in Bombay, she conceived and did not miscarry as in the past. She had a son, whom she named ALLA RAKHE popularly known as BABU.

Subsequently she had another child called Shabbir, who is now 3-4 years old. She lost her husband soon after this child's birth, and decided to stay on in Bombay rather than go back to the village. Here, she was able to feed herself and her two children and find work. Besides, she was independent and need not depend upon relatives, who were uncaring about a widow.

She used to be very untidy and looked like she never combed her hair. Later in discussions, it emerged that she was expected by the rest of the people to be like that because she was a widow. Combed/tidy hair was a sign of seeking attention.

While she seemed to think that she could feed herself and the children, there were a series of mishaps which occurred one after the other. The most traumatic was that since she lived on the street, when she went to work, her children sat or played on the pavements. One day, while playing, Baby went on to the road, and was run over by a bus. Luckily he escaped with a multiple fracture in one leg.

He was immediately taken to the hospital, his leg was set and after two months the cast was removed. He must have been asked to do some exercises, but she claimed that the doctor did not say so, and as a result, Babu could not put weight on the leg, which was now slightly bent. He started dragging his leg.

It was at this point that the women's groups were formed and in one of the many experience-sharing meetings she shared this trauma with the group. She also seemed to come to the conclusion that she was very grateful for the help she got at the time of the accident, but her feelings after the whole experience was that the hospital frightened her, she would not have been able to go there on her own, and that nobody there cared for her child. Now, he could not even walk.

This led to a discussion of why such accidents occur, what are the measures possible at the time of crisis like this. Safeeda then related details of the entire experience and it became a lesson for the women on how to admit an accident casualty into the hospital. Some very interesting details emerged. For instance, all the women used the ward boys as the ones who would give help. The ward boys would negotiate a price for this assistance and make the admission into a favor, possible only, because of their involvement.

Behavior of each member of the hospital staff was given special significance. For instance if the nurse just smiled, then she liked the patient and she was absolved of all future

neglect, under the excuse that she was busy. On the other hand, if any of the staff yelled at them in the beginning, then they were bad, did not give medication and wanted to harm the patient. It almost seemed as if much impressions were stamped into permanence based on incidental, initial reactions at the time of the crisis.

Since Safeeda stated all this in the group meeting, most of the women felt very comfortable to express their similar experiences at that point. No opinion was expressed by the workers. Instead, we were ready to accept these statements at face value. We decided instead to develop for ourselves and for the group, views on this subject based on shared experiences. So to start we decided that we would collaborate with Safeeda in initiating investigation about whether Babu would be able to walk normally.

Over the next three months, we had our first taste of how indifferent the hospital is to the poor. She was on her own in the beginning but after her third visit, (after three weeks), she came to see us to one of us to accompany her to the hospital. Our first visit was a disaster. Then, through a burst of inspiration, Leena chose to act like a doctor, breezed through all the formalities, and demanded something be done.

What occurred after that is history. There were sets of doctors, one wanted to operate and while another did not. Twice he was admitted for surgery and brought back just before the operation. Throughout this period, several of the staff and volunteers accompanied Safeeda to the hospital. While this dialogue between two sets of doctors continued, we all waited very patiently. Finally, when it occurred the third time, there was much furore and shouting.

As far as Babu's leg was concerned, the doctors were now apologetic, and gave us a series of physiotherapy exercises to be followed. At the same time, they seemed curious as to why so many people were interested. At the meetings, these experiences were shared. Interestingly, at that time, many other women who had problems would seek to go along with either the volunteers and Safeeda to the hospital. Without realizing it Safeeda, who considered herself to be helpless and unknowledgeable began to show others how to use the hospitals. Infact, what began as a tentative strategy is now a practice.

For instance, it is now a matter of common standing that no woman goes alone to the hospital, she always goes with a group. As a result, there is less indifference to face and many brains working together. Over a period of time, we have been able to understand the hospital hierarchy and how different OPDs work, so that there is better management of time. People know how to get case papers, what are the hours of various OPDs, and gradually, have evolved a growing confidence in dealing with this large hospital machinery.

We had found that in the past, whenever the patient went with a letter from the doctor, he or she was promptly dealt with. In the beginning, we put that to some kind of doctors' code. Gradually, we began to write official sounding letters on a special letter pad, and we would ask the doctor to reply on the letter stating what the diagnosis and follow up was, for us to be able to understand the problem. The result was fantastic. It seemed that the patient felt boosted with the letter, which they considered as a special privilege. What

the letter did in reality was that it identified the exact OPD, the doctor whom the patient had to see, and described, although briefly, the nature of the complaint.

This made communication clear, and since patients insisted in getting a written reply 'for didi's' who wrote the letter, we were able to explain to the patient on her return what exactly the ailment was, and what treatment was being given.

During meetings, all these happenings were discussed. Women, who had experiences to relate would do so, and with the help of the workers, these experiences would be analyzed. As a result, there was a definite impact on the second visit to the hospital. In the beginning, the doctors attributed this to us, commenting that we were taking special care of the patients we sent through our agency. However, gradually, as patients took others, demanded the same treatment, wanted explanations, all of us were collectively branded as those 'people from Nagpada'.

Over a period of time, there was a great feeling of security among the women in consulting with the Centre about what the doctors said. Often decisions had to be taken about hospitalization and treatment. All this was discussed with the staff at the Centre. Usually, each instance like Safeeda's was dealt with on its own and as many of the neighbours who could be involved were roped in to help out. At the time of meeting, they were encouraged to share this with the rest of the women, with a little help from me, the staff and the volunteers in twisting the event around so that the various facets became of educational value for them. By implication rather than by action, we were able to show that government provided services were funded by money from everyone's pocket, and the poor had as much right to the services as the rich. The hospital was not going to open its arms and invite utilization of its facilities by the poor. Instead, the poor, who otherwise spent such a large portion of their money on fees to private practitioners and medicines purchased could understand the medical services, and learn how to use them. Then they could demand these services from themselves.

Khodeja and Mairun:

In 1982, through the routine check-ups that we conducted for various groups, Mairun, the 4 year old daughter of Khodeja was found to have a severe nutritional deficiency. For this the doctor had to give her six vitamin injections. While undergoing this the doctor screening her out for other illnesses, found that she also had TB. She had to have 60 streptomycin injections.

We arranged with the TB clinic that we should be given the drugs, and that we would give the injections. So we called Mairun and asked her to get her mother to the clinic, and we planned to work out the details of the treatment with her. When Khodeja came she struck us all with her quality of 'quiet strength'. She hardly talked, she listened a lot, and always got another woman, usually Safeeda, who could translate for her in their Bihari dialect, that all the people living on the pavement spoke.

She was not a member of the group at that time, she stated that she had to go and work, and that Mairun would come on her own to take the injection. We were quite worried about this and we felt that this might mean we would have a terrified child on our hands. Mairun turned to be quite the opposite. She would come everyday exactly at the same time in the afternoon, and she would proceed to call Sunanda, our nurse, from whatever task she was doing, jump upon the bed, and calmly wait for the prick of the injection on her rump!

Gradually, all the other children who were part of the non-formal education program which NNH runs, (called the Happy Times club), would accompany her and ask to be allowed to watch this daily routine. Once Mairun's treatment was established, we were now ready to check the rest of the family. We were absolutely depressed with what we found.

Khodeja's husband was a TB patient who had started treatment but had stopped midway. He was not absolutely clear, but he was also very sick and refused to take treatment. Khodeja was pregnant, and due to deliver any time. She already had three children, of whom Mairun was the eldest, then two sons, of which the younger had a heart murmur, and was very vulnerable to infections, coughs and colds. Khodeja worked as a house-help in three houses, and earned for the family while the husband who was too sick to work, looked after the children. At that time, there was nothing we could do to make her husband take treatment, and instead of arguing uselessly, we decided to wait for the right moment to do any further convincing.

Khodeja's baby was born on the pavement one night late in September that year, and as a matter of interest, I shot a picture of her and the baby and the family and put it on the bulletin board.

Around that time the meetings began and Khodeja began to attend the meetings. She would always come a little late, sit quietly through the meeting, never open her mouth, and leave. Only her intense concentration indicated her involvement in the proceedings of the

meeting. During the next three months, Khodeja went through the most harrowing period. Her son Zakir, who had the heart murmur, had measles and had to be hospitalized. Soon after that the new born baby was very ill, and was detected to have primary cox. She lost her job, had to be in and out of the hospital, and during that time, most of the pavement dwellers got together to give their family food.

Volunteers and staff of the Centre would work out her hospital stay for arranging necessary medication, getting doctors to finalize the diagnosis, and to explain to her and the rest of the community what had happened. Sometimes this would be done at the meetings, sometimes in smaller groups. It became evident that the feeling of the entire group towards Khodeja was similar to that of our staff. She was a very special lady.

At the next meeting that Khodeja attended, Sakina already begun to relate about the TB experience and she and all of us stressed the need to be very clear about the dangers of proximity with a not completely treated TB patient. A few days later, Khodeja came up with Safeeda and Khaneja and stated that they wanted to have a discussion with me. It was her husband who was not taking treatment and therefore causing these bouts of ill - health. She said that his wife, she was willing to be the main financial support of the house. She was ready to reverse role of husband and wife with him, but she was not ready to do this at the cost of the children's health.

She also stated that she was just over one very major crisis in her life, and had come out of it with the help of NNH and all the people from the community. But she was frightened of having to face it again. Now she had just managed to get a job and soon she would get more, but what was she to do with the feeling of guilt that she had? Her husband was not only infecting her - the children, he was infecting the rest of the community, and the very same people who had cared enough to support her. Besides, they were were living in the jhopda of Khaneja, and Khaneja had a child...

We all listened in stunned silence. There was nothing that had prepared us to hear with such clarity the synthesis of all the information we had generated and dispersed. So I asked her what she wanted to do. Surely she had not come up only to explain all this to me. She took a deep breath and hesitantly said that she and her husband had argued about this subject the night before and several times before. Her husband was of the opinion that the drugs harmed him, and that she had no right to demand that he undertake treatment. He was the man, he was her husband, and she had better listen to him. So she had said that I had threatened her that unless she brought her husband to me and got him started on the treatment. I would encourage all the people on the pavement to isolate him, I would not allow Mairun to come to the centre, and I would stop all the medical treatment that I was giving her.

I was absolutely flabbergasted! What in the world was I to do now? Did I really have a choice, I wondered because Safeeda and Khaneja said that they were already circulating that rumor and that they had arranged for two of the other women to confirm this by telling it to Mohd Muslim, Khodeja's husband. I was very curious as to why they had thought of this particular strategy. Khodeja had her answer ready: she said, that she was

very fond of her husband and he really was a nice man. He was a better husband compared to all the other men who lived on the pavement. Since his illness, he was just not ready to take medication and all the time he would find excuses to not take medication. In the past, she had accepted this type of statement calmly, feeling that it was her 'naseeb'. Now, over the last six months, she had begun to see that there were many alternatives which were open to them, but unfortunately, although she was convinced, she could not make him understand. She knew that he would die if he did not take the medication, and probably kill her and the children. So she had decided that she would use this strategy. She knew that her husband, like all the men on the pavement outside were in awe of me.

This awe was partially due to the way I expressed myself. They were also sure that my support was always with the women, and, that during crises, there was always help. While this was comforting, it was also awe-provoking according to Khodeja, and she saw no reason, why with a little play acting it could not work out. After all, she had heard at one of the meetings, that a woman from another group had threatened her husband who had come drunk late one night, that she knew my address, and that I had specifically asked her to take a cab and come to my house if her husband got violent. And her husband had gone off to bed quietly!!

So now, Khodeja's husband, very frightened of what this "dragon" was going to do to him, came to see me, and we arranged for him to be taken to the TB clinic. We assured him that we would be very helpful, that we would assist him and that he should not worry. Nothing we did or said could convince him that the drugs would not kill him.

The doctor at the clinic said that he had abandoned the treatment twice before, and as a result he was now ready for the last line of treatment, and that if he stopped halfway, then it would be very difficult to do any thing. We talked about this to him, to the people who lived around Khodeja, and in the women's meetings Mohd Muslim began to take treatment.

All went well for a month, but suddenly, one day, Khodeja came up to me stating that for the last few days, he had stopped taking medication, and that he now refused to take them. In her anger and frustration, she had told him that she was not going to look after him now that he had stopped taking medication, and that he had a choice of either staying with her and taking the medication, or he could leave the house and go. He had decided that he would go and he had taken the train the night before and gone back to the village.

She talked for a long time, first with me alone, then in the group about her mixed feelings, and admitted she could not decide how to judge her own actions. What struck all of us at that time, was that the groups who heard of her story, extended support and sympathy to her as a friend, and talked about how they would have handled it but no one passed a judgement on her action. Many women shared their own worries about people in their own house who had TB and who refused to stop spitting or take medication. They all admitted that in their hearts, they would also give priority to the health of their children, but none felt they would have the guts to make such a confrontative choice.

For almost 6-8 months her husband stayed in the village. At first, he was spreading rumours that she had deserted him and was living with another man. Khodeja was very hurt, and would often say so, but she seemed to magically get support from all others. At one time, one of the relatives who had gone to the village, had challenged her husband in a meeting of the "jamat," and related the entire episode of what had really led to the reason why Mohd Muslim had left.

Khodeja gradually began to settle into a routine. Her youngest son, now two, was in the crèche, all the older children were attending municipal school, and would attend the Happy Times Club in the afternoon. Whenever she had time in between her various jobs, she would come up to the Centre with friends or alone, and quietly sit and listen to whatever she found was happening around her, and accepted the roles, we pushed her into in her quiet dignified manner.

For instance, she would relate her experience with taking patients to the clinic, or to the hospital, or about how she had admitted her children to the school - often she would just relate what was happening in her life, and gradually, she also began to talk on her own.

Suddenly, one day, her husband arrived back in Bombay. Two of the relatives who had gone to the village had found him on the verge of death, and forced him to return to Bombay with them.

He was in a terrible condition when he arrived. Within a day, he was taken back to the clinic, and they said that he had deteriorated, and that he would have to be taken to the Sewri Hospital. When he was taken there, the doctors advised that we hospitalise him until they completed the investigations. When the investigations were completed, they told us that the chances of recovery were dim, but if we still wanted to pursue this, we should admit him into one of the sanatoriums in the suburbs.

We did that, and Khodeja would go once a fortnight to visit him. It was amazing the effect each of these visits had on her, they seemed to drain her completely and she was torn between feeling concerned for what was happening to him - feeling sorry for the state he was in and at the same time resenting the manner in which every few months he broke down whatever semblance of normality she tried to bring to her life and that of the children. She would share this so honestly with all of us, that it was a lesson to everyone, on how we all live with dualities in our existence.

A few months later, the sanatorium closed down, and we had to shift him back to Sewri Hospital where the doctors were openly hostile to taking in a terminal patient. After great persuasion they agreed, but after a few days stated that the patient did not eat, and neither did he take his medication. So Khodeja, our nurse, the ambulance driver and some other volunteers took turns to be there at least at meal times to feed him and to make him take his medicines.

It was no longer only Khodeja who was involved, we all were. It was as though, we were all fulfilling a commitment that we had collectively taken, a responsibility that arose from

the fact that we had all shared knowledge which had made us sensitive to what had happened, and we wanted to see it through to the best of our ability. We all knew that he would die, but we would try as such as we could.

And finally, he did die. Early, one rainy morning in July, the ambulance brought him back, after all the formalities were over. All the people from the pavement pooled in money for the funeral, and one of the women for whom Khodeja worked, sent the shroud for the body. Her uncle gave her a white saree, and Khodeja sat dried-eyed while all this happened.

She stayed home for a day, then went to work the next day. She was listless and we were all worried about her. A hysterical woman we could have comforted. But Khodeja... she baffled us all. Two days later, she found that her nephew, Samiulla had Rs.4 in his hand. She asked him where that came from, and he said, that the teacher had asked him to sell four notebooks of the 10 his father had bought for him at a subsidized rate from NNH.

She took him to the school, and to the teacher and very politely asked her to please return the notebooks to the child and take her money back. The teacher miffed at the way this illiterate woman was talking to her asked why? Khodeja gave her such a dressing down. She said that the notebooks, which cost double the amount, were specially provided to very poor children as an incentive for parents. They were not to be sold. If the teacher wanted books, she should find out for herself if she was eligible and seek to take them directly, and not from a child who would not understand the significance of such an act.

She came to the Centre after this, calmly related the incident to all of us, and stated that she was really concerned about how much she had to learn, and that every step of the way, women had to keep thinking about whether what was happening was for their good or not, and she had finally come to the decision that she was not going to wait to listen, - Now - after work, everyday, she would come and spend time at the Centre, learn and help others..

Self Medications: "Dear Dr. Gazadar" and her magical medication

Some time at the end of 1983, we felt that as a collective, women had developed a fairly well worked out conception of health and the usage of medical facilities. So far, we had been very supportive, always taking their side, and twisting the rules and regulations to make them work for the people. We felt that having reached a state where doctors and medication did not frighten the people, we should now move into new territory. At this point I want to state that all the women were not comfortable, only about half in the group could be in that category.

So at one stretch of six group meetings, Dr. Mona Saxena of NNH spent time with the groups, trying to make them understand the point of view of the doctors and the hospital, with a view to helping them to understand how routines were established, admission procedures, methods of doctors examining the patients, the problems of very large numbers, the hierarchy within the doctors and nurses, etc. At each point, several instances were related by the women, and we were able to work out very meaningful discussions. Then, we moved to the problem which Mona felt very strongly about and that was the constant complaint of patients about 'Dawa ki assar', or the value and effectiveness of the medication.

She told them about the fact that most doctors usually start off initially with the lightest medication... i.e. they should start with the lightest and least complicated medication. On finding that it does not work, they move to the next level, and then the next. Often patients, either do not want to wait until they have reached the right dosage, or often, due to impatience, they switch doctors, and do not tell the second doctor that she has gone before to a doctor earlier, and as a result, start another first course, and consequently not have any effective medication. Then, one 'smart' doctor would start off with a heavy dose and... the patient felt miraculously better.

As a result, there was a lot of discussion about doctors. Women judged the effectiveness of the medication on the basis of how quickly they got to feel better. This, they called the 'touch', or 'haath ki goon'. While this conversation was going on, Zamila Gazdar, wanted to tell her story.

Zamila is a recently widowed woman, who was very comfortably off when her husband was alive. After his death, she found that she was in a series of financial crises, and so far, she has resolved this by pleading to the well-wishers to do something for a young widow with two small children. Her son Abbas is malnourished, had a series of small infections, which were all treated at the Centre. Zamila was a very charming woman, who was fun to watch, so long as she was not interacting with you. Then it became a strain to tell her not to put on such a heavy act. Anyway, as far as she was concerned, she made the things move her way ...

In the group, she was a very attention seeking personality, always opinionated, spewing inane phrases, which were part of the repertoire that she had developed, and she always refused to accept others' points of view. Invariably, she would put herself in a position of taking exactly the opposite views from the trend of the group, then get into an argument about it, generally lose, and then weep about her poor circumstances, and how as a poor widow, she was helpless, had no knowledge of the world so on...

So at this meeting, she wanted to relate about her method of dealing with her own medical problems, and she started off... She said that she had been suffering with a terrible pain in the joints for quite some time. So she visited several doctors, and told them at great length that she could not live with such pain. Many doctors would give her medicines, and she would try it and it would do her no good. Finally, she must have gone to the nth doctor and wept at his feet, stating that he must do something for her. And... he

gave her the medicine which stopped the pain. But he had asked her to come again to meet him after ten days. So she went to meet him after 10 days, and he asked her to take another medicine, she tried it, but found it did not stop the pain in the manner that the other one had, so triumphantly she said, you know what I did??, I started that older medicine. Now for the last 5 years, whenever I feel the pain, I just go to the shop (Chemist) and buy it.

We checked with her, she seemed to be using "Prednisolone" which is a steroid,! Mona was ready to tear her hair. Now after five years of fairly regular use, she could not stop this at once, at the same time, to continue it was bad. There was a lot of discussion regarding this matter. The group was able to understand at that meeting some of the implications, and over the next few months, we were able to discuss the value, and harm of medications. Zamila Gazdar's story, sometimes told by Mona or by us would be the introductory vignette leading to the subject of use and abuse, of all matters related, but Zamila Gazdar could never be convinced that she was not smart in doing what she did, nor could she be convinced to gradually reduce the dosage.

She happens to be a very unusual member of the group, whose contributions at that point and during other sessions became a focus of attention and taught the other women many concepts but sadly, Zamila never got back as much as she gave to the group. She finally stopped coming for the last six months, and we are trying to locate her after her change of residence to see if she wants to come back.

Women by and large do not follow a full treatment plan either for themselves or for their children. Often antibiotics, which should not have been prescribed in the first place are taken for a short time, and this develops in the patient's body a resistance. So far only some of the women have understood it.

Rehmat and her son who had scabies.

Rehmat is a young 19-20 year old woman who has a 3 year old son. She is a volunteer who comes very often to the Centre and brings her son as there is no one to look after him. One day at the meeting this normally happy and placid child was very upset. So when we asked her, she opened his shirt and showed us the infection he had on his back. She said that since it was the weekend when this had happened, she had bought medication from a doctor but it was not giving any relief.

It was very obvious that it was scabies so we decided that we would use that as a topic of discussion. Someone asked her if she had ever seen such an infection before so she and rest of them after some time identified it as "kharooj" the marathi word for scabies. We discussed what it is due to, why it spreads, how it spreads, how it can be prevented and how to treat it. It seemed from the conversation that she had had with the doctor (or at least her version) that he had given her tablets and a cream and since she did not have it, we all went to the medical center, confirmed that it was scabies and showed her how to apply the Benzoate on the child.

Four days later, at another meeting she brought her son with her and the whole bunch of women who were with her were giggling and kept nudging her little son to tell me something. When he refused and hid his face, Rehmat said that the scabs had dried in two days and the little fellow was so pleased that he went around telling everyone that Sheela didi had cured him. The crucial part of the story was still to come. Another lady's (popularly known as "phoggewali") husband was lying down and scratching himself and this little boy dragged Rehmat to him and told her to give chacha the "didi wala dawai".

It was applied and he was cured. So the women wanted to know if it would be a good idea to go around their slum and not only teach the younger children to identify scabies but also tell how to deal with it just the same way as they had identified families needing immunization and told them what to do. This way, even infectious diseases could be contained.

After that, they did go around their slum. In one slum, we gathered all the children and made them examine all their friends' bodies to see if they had any infections and then marched them all to the dispensary, where they applied BB on each other and talked of how painful the itch was and what to do about it.

PART TWO:

LINKING PAST MEMORIES TO PRESENT DAY ACHIEVEMENTS

It is considered "routine" in fact quite typical among the communities of the poor (especially those which have been referred to in this report) for an educated person to "capitalize" on experiences they (the educated) were a part of. Too polite to confront... it is expected behavior of social scientists, journalist to get excited with all the information that they get, the insights which they develop. So almost automatically, the "natija" or result is "kajaj kala Karna"(to ink a white paper black.. and write about it... either to earn money or fame... is the interpretation women give to such behavior.

Most colleagues in the field of social sciences and health have leaped in the defense of their behavior and felt angered as aspersions cast at what they consider valuable data documentation. How else will theories evolve? Few, however persuade this conversation with us. They accepted that what we were presenting is a point of view expressed by women and communities of the poor. To that effect it was a valid point. It has in fact been these discussions which gave rise to such form of writing. Later in the end of the report we pursue these issues and present the possibilities we see in it.

The departure that we saw for ourselves in this experience was related to issues linked to health on the one hand, and the issues of knowledge creation and its ownership and use. Let us take issues of health first. Health interventions are part of a larger development and change process which is affecting large numbers of poor. "For their good", many changes have been identified as "good", tremendous investments have been made in alternative infra structures and training and personnel...but none of these have sought in any real terms to include the perspective and contribution of the very constituency which this enormous delivery system is seeking to address itself to.

While the manner in which the poor are treated as a group is bad enough, the manner in which most development policies view women many times worse. Women are wombs...is what poor women would say if their language allowed them to express this succinctly. But poor women communicate best in their own way, another little story to illustrate!!!

In one of the endless meetings we have, women were discussing issues related to health, hospitals, and doctors. Several women were older migrants, while others had come more recently into the city. Said Lakshmi, a recent migrant that she was finally convinced she should go to the hospital to check out her pain in the stomach...maybe that treatment would suit her she stated. Krishna, who was sitting next to her asked, is this your first time? Yes said Lakshi, it is the first time, I had all my children at home. How many children? she was asked... 5 she replied. Well, chanted several in the group, when you go to the hospital, and the doctor comes to check you up, the first question you will be asked is : How many children do you have... don't say 5, say 2, and say your husband has had a vasectomy! But why do you want me to tell a lie? It is not to encourage you to become a liar, came the reply, it is the only way they will focus attention on your stomach ache!!!

It has been a longstanding goal of this process to make women from slum communities central actors of change processes. Health is one of the "soft" areas... one which even hostile Municipal Corporations, state government and august bodies like the world bank promote as necessary of homeless and vulnerable population whom they consider "illegal" and unwelcome into the oasis of the cities resource structures. In the next set of stories we link up processes which we began in 1980-81 to events in 1990-91 to demonstrate the alternate possibilities which can occur if investments in processes are made among people and they are allowed to benefit from them as well.

This is the "story" of immunization of children. It begins when the women's groups began their own immunization work.... and the use made of a city wide campaign in 1991.

Our own immunization campaign 1980-83:

For a very long time, at least over a period of two years we had been encouraging women to get their children immunized. On the whole, the experience was very dissatisfactory. It seemed that women would undertake the immunization only in the context of that particular immunization, and were unable to really grasp the meaning of the concept behind it.

Usually some external pressure compels the woman to get a child immunized. She does not understand the context, she does not know that particular dose of immunization is not all. Neither does she utilize this knowledge for the benefit of either the same child in the future or for the other children. In short, she just manages to do what she has been told, at that particular time, because the person who told her to do so, is in a position to demand that behavior.

In very rare cases, a woman with a small child would go in for completion of immunization dosages. Our reason for focusing on immunization was not only because we were concerned about the low level of immunization, but also because we realized that dosages were completed only in one third of the cases. So we started this experience with a clear idea of what we felt discontented about. To seek answers, we turned to the women in the groups. There were some women who had in fact got all their children immunized. These women seemed to share some very interesting features. They were women who were generally familiar with the hospitals and clinics and were on good terms with the staff. They had either accidentally or otherwise absorbed the concept of immunization as being good for their children.

We had several small group meetings in which we showed these and other women films about immunization, flash cards about types of immunizations, and also about methods of immunization. However, we found that all the answers were very mechanical, and all the women seemed inclined to accept that immunization is good for them, because we said so, or the doctor said so.

So initially in a small group and then in a larger group, we took up the task of first examining what women perceived (on the basis of the information that they had) immunization as. We had a very wide range of answers, some were close to the truth, while others far from it. Some women treated it as though it was a "tonic"... they said it was a medication given to children which made them stronger. Others said that immunizations differed on the basis of whether they were injections or were oral. According to them, even the X-ray done to check for TB was immunization!

There were several answers and synthesizing all of them clearly showed that most of the women had some exposure to immunization, but as a result of their experience, they had a very mixed version of the concept of immunization. It seemed as though the interest of the organizers of the health program was related to the immediate action of immunization of the child, and the role of the mother was a matter of interest only as far as making her co-operative in this venture. As a result, women seemed to retain messages, which after a period of time got washed away.

We had enough experiences in dealing with women now, to seek a method of sharing information, which would seek to not only help women attempt to resolve some immediate goal, but also serve some long term purpose. As in all our other instances, we felt that immunization to be an issue which was a powerful one. It would serve to reduce the morbidity of children, and would ensure women's' participation at any given point. It would further make them capable of repeating this exercise on their own, for the same child, or other children, as well as become agents of change for others who are in their sphere of influence. Our goal was more ambitious. This experience as a whole should help build a foundation of women, taking on action after thinking about it, and feel more confident about initiating actions on the basis of their analysis of the situation rather than persuasion by others.

While the order in which the following events occurred was not as systematic as it seems in writing, this was more or less the sequence in which they occurred. First, we sat down and discussed what we thought was immunization. The discussion ranged from protection from disease to strengthening of the body. The dosages, the method of administering it, the purpose of the immunization was not given much thought, in fact the very confusion was due to the fact that all these various factors were mixed up.

So we began with the basic concept of "Immunization - What is immunization?" We found that it required more than the very simple conceptualization. This concept is based on a series of other concepts. So we tried various means - for instance, each person tried to explain it in the manner they themselves understood it. Then the person sitting next to them had to repeat it, and then the group had to state whether it agreed with the manner in which the explanation was given. Finally, we tried a over simplistic example - Everyone was familiar how their bodies reacted when they undertook a physically strenuous task for the first time.

Whenever the body had to do something new in the form of physical activity, it was some time before the muscles got used to the new form of strain, and so, whenever we

anticipated that in the future we have to take up a new activity, we would try to prepare the body for that activity. So making your body go through "practice" of physical strain would make the "real thing easy to deal with.

Drawing the analogy to immunization, it was explained that due to the advances of medical sciences, now it was possible to know some of the battles that the body has to fight in order to fight the germs which attack the body. So, in order to teach the body how to fight the germs in case of a real attack, there was a method by which dead germs would be put inside the body and this would help the body develop a mechanism of fighting off the real germs.

It needed to be explained several times before we were able to get the women to understand this and relate it to others clearly. Once that was done, the rest was much easier. Infact on hind-sight, we felt that this basis of explaining immunization had not been considered. Once this was understood, then the rest of the information could be assimilated quite easily. So the next thing we went on to discuss was the kind of illnesses that women recollected in their childhood as killer diseases. They listed typhoid, cholera, smallpox.

In each of these instances, we drew their mind to the immunization that they had either undergone themselves, or which they had seen their children take. While all of them could recollect the smallpox vaccine, due to the marks, there was confusion about the typhoid and cholera. It was only after we talked about the children getting this vaccine every year in municipal schools, the pain that it causes, that they recollected it. Many sheepishly confessed that they never sent their children to school on that day.

From this we went to all the other diseases that can be withstood due to immunization such as TB, polio, tetanus, diphtheria, whooping cough, and now jaundice and measles.

We then moved to the schedules that are necessary and how from the time the child is born, one has to keep is schedule in mind. We also elaborated the different methods by which immunization is given, oral or muscular. For all this, we had to stimulate them into recollecting past experiences. We spent a lot of time making them recollect the reactions they had when their children had their "shots". Most of the women, as mentioned earlier, went because of their faith in the doctor, or because their neighbor had said this should be done.

We then presented a possible strategy for action to the women. That we wanted to get as many women as possible aware of the concept, and to encourage them to ensure that their children are immunized. After much discussion, we hit on an idea which appealed to us all. We decided, that we would first of all talk to the women of the various groups, and once they were equally enthusiasm, and able to appreciate the need of having all the children of a certain area immunized, then we would suggest that each group interested would assist the volunteers' group to enlist general participation of the women of a given area.

The women of the Apna Zopadpatti were the first to agree. So about 15 women and volunteers went there one afternoon and divided themselves into 5 groups and covered a small number of households. Since we had several women from that area, they knew which of the households had children below the age of ten, (as we had decided to concentrate on triple antigen and polio). So in about one hour we not only had a survey of how many households had such children, but we were able to work out how many of these children already had been immunized, who needed which dose, who needed boosters etc.

We then proceeded to give them an officious looking referral note and retained a copy ourselves. On this letter we wrote the names of children, their ages, and what immunization needed to be given, the name of the women was the main feature, and we would work out a specific time when they would go to the clinic (so that at each given time, four to five neighbors would go together and would also remind each other).

At the clinic, the nurses and the social workers had made a master list of the names and so as the children came, they would be ticked off. Those who did not come would be then reminded by the local volunteers. They would also be given the date of the next dose, and asked to help each other remember when to come ... While all this was going on, we would all reinforce the necessity of maintaining immunization schedules, and help women recollect about past experiences about immunizations.

Apparently the most common problem seemed to arise out of mobile medical vans which come and give medication and immunization at the same time, and often do not come back to give the second dose. People did not seem to feel that they owed a responsibility to themselves and their children to find out all the details about who these people were, whether they were coming just this one time or on a regular basis. It seems a terrible waste of time, personnel and money to have muddled up services like that.

Whenever we got news of a new born baby in an area, we would encourage her to go to the hospital for immunization, in fact we found that many women thought they could go only if their child was ill. So over the next three months, women would keep coming.

So far as the concept of immunization was concerned, we had now hit on an effective methodology to explain it to the women. Those who learnt were able to further test the extent of their knowledge by trying to explain to others. And since we were now able to work out a method by which we could actually insure the participation of all the mothers of that slum, we felt confident that this kind of a multiple exposure of action and word of mouth would gradually fulfill the expectations we set for ourselves in this kind of work.

It is also very important to state at this point that by no means is one round of such an exposure the end of this experience. In fact, we feel that it would take at least two to three years of yearly appraisal on the status of immunization to help reinforce in the mind of the women, all aspects of immunization.

We seek to describe in this experience an attempt to pool all knowledge that we had to evolve a strategy which would work for us. This was based more on knowing what did not

work, what we want and trying out several methods. In a limited way that process continues in the specific geographic vicinity of those groups.

Ten years later, another series of events gave us the opportunity to expand on these insights and to finally begin to harness our collective insights into something which had city wide, and hopefully larger urban implication.

"Making Immunization our Business"

A short report of events which occurred in Nov-Dec 1990, which we believe have a crucial influence on our work in the next few years. Written by SPARC, Mahila Milan and NSDF 1991.

INITIATING COMMUNITIES TO SPEARHEAD THE CAMPAIGNMUNISE THEIR OWN CHILDREN.

A story of how we all got involved in this process.

Sparc, Mahila Milan and NSDF are three partner organizations. They comprise of different kinds of people, men and women, educated and illiterate, who have decided to seek many ways to ensure that the poor in the city... most of who have come from villages, learn to understand how the city functions, and learn to ensure that it provides them all the facilities that it is meant to provide.

This had led to assisting groups of men and women from poor settlements in the city to learn many new things, to understand better their own situations, and to develop capabilities to undertake many new activities which would lead them to gaining the rights and recourses they want.

Immunization... this is the vaccination which the government has decided to give all children free... to help children withstand common diseases is one such service which is provided through the Bombay Municipal Corporation. Its health centers provide this facility to all residents of the city. By and large, most community people know of Immunization "TIKA", and over the years more and more people have been immunizing their children.

In November of 1990, the Bombay Municipal Corporation announced that it was not satisfied with the statistics that it had on Immunization. The figures were very low, said the Municipal Commissioner, and he sought the assistance of the citizens to assist him and the corporation to find out why this figure was so low.

It was around that time that we were approached by UNICEF.. which was seeking support from various voluntary organizations to support a campaign for better immunization. In that meeting, SPARC, MAHILA MILAN AND NSDF were asked if they could prove any assistance.

What assistance could we provide? We have so far not got ourselves associated with such activities, besides we also felt (at that time), that the BMC employed staff to do all this work... so it was their job to do motivational work.

But then, the children who were so far not immunized were the children from poor settlements... our children! This Immunization was a resource which was our due from the state, and making sure that it reached the children was as much within the purview of our

commitment to ensure resources allocated to the poor reach them, as say for instance water, or electricity.

So then what is it that we could do, which was not duplicating what the State had to do? What were the reasons why our assistance was being sought in the first place?

In exploring this process, we felt that the State can make available a service. It can create an educational campaign to inform people that the service is available, and in some instances actually plead with the families to use it! But that did not necessarily imply that people used the services.

We began to explore why people may not be using the services. We thought of several possibilities. It may be that the people look upon the service with suspicion...they do not understand Immunization. It maybe that the communication system is faulty and people are unable to understand what the educational campaign is seeking to tell them. It maybe that the services are not available as and when stipulated, that the delivery of vaccination is not suitable to people, not within their reach and so on. Or it maybe that people have not felt the urgency to participate.

So again the question, what can we do?

Oh many things... and ideas began to pour in as various people who were participating in the discussion began to share possibilities:

All of us in this network KNEW this target population.. after all they were US. We knew how we reacted when we saw posters and banners and advertisements meant for us but which we felt were dysfunctional. Besides, ads and commercials sold soap, just that form was not sufficient to motivate us to do something for our children. We knew this to be an issue to influencing community values. Our leadership and our women's collectives would have to promote this as much through word of mouth as by this campaign.

But some suspicions remains... after all this campaigning and motivational work, will children brought to health centers be given vaccines? It was essential that we had some "control" or say in this process. After all, our credibility was at stake. We knew that we would only get involved if our final objective of effective Immunization was achieved.

Both the Bombay Municipal Corporation and UNICEF assured us of that. All health centers would be informed. All areas where there was no health center nearby would be have mobile vaccination centers set up nearby for the children to be vaccinated.

Dear God, but just look at the time we have!!!! These discussions were in the last week of November, and the campaign had to be started in December and finished by the middle of January!!!

How many households can you cover we were asked. We began counting the membership of various federations. And we came up with a crazy number...3,50,000! So many? are you sure? Yes Ofcourse.

Formulation of the campaign:

The most central part of the campaign was the personalized "knock on door" campaign. Through this process it was ensured that the network of the Bombay Slum Dwellers Federation (BSDF)*, would knock on the door of each household and check if there were any children below one year old. If there were, then they would ask if the child had been immunized for measles. If not, then the child and the mother would be given a Immunization card filled out with the child's name, and directed at a particular time and day to the nearest primary health center.

In all instances, the volunteers and leaders who would undertake this house to house survey would have already spoken to the doctor of the PHC and confirmed the timings. In all instances the first batch of children would be accompanied by the volunteers.

A poster designed and printed through the network members (in two days) and in 5 languages, would be stuck in each settlement. It would have written in it how many children need to be immunized, along with the campaign messages.

Banners and posters were also strategically designed and placed. The campaign sought to provide local leadership support to promote this campaign in their neighborhood. Do in the pamphlet, as in the posters, local groups were at liberty to put their own names rather than sparc, Mahila Milan or NSDF. All this was in creating ways by which people could feel a greater sense of ownership over the campaign.

Similarly, when UNICEF representatives came and talked to the 50 key leadership of the network, a video of about 45 minutes was taken. This was duplicated and circulated to many areas and used when other leadership was harnessed into the project. That tape was their... As was a copy of many UNICEF sponsored advertisements on Immunization. Everyone was given copies each had to use their own imagination to harness this.

The PHC staff and the teams from the mobile vaccination campaign were a new entity for interaction. There were a few initiate "skirmishes" In some instances they felt that maybe this campaign was a result of their failure to achieve targets, and their interaction with volunteers began in a defensive manner. But the campaign fever soon got rid of this. And a more positive partnership began.

By the time the earlier target was achieved, demands began pouring in from the various ward offices of the BMC seeking the assistance of the volunteers to help them in areas they had difficulty. As one doctor aptly stated..."your intervention liberates me. I can now do a doctor's job, you make sure everyone comes here!".

A totally unforeseen contribution came from the street children from "Sadak Chaap". They performed a street play which was absolutely fantastic. In the play was an abnormally large injection being administered after much role playing to a child. All the children wore T tea shirts with a message "have you immunized your child?" written on it.

In one instance, the crowd gathered around this bunch drew the attention of a policeman who came and inquired... street children tend to generally run from the policemen... but in this instance, the child in view saucily turned around and asked the policeman to read what was written on the T shirt saying, "Policeman, have you done this? If not, go home and take your child to the health center!". This episode was such a hit, it was soon incorporated in the play.

All of us who participated in this campaign have been very touched by the participation of almost 300 such street children. Imagine kids who have run away from their homes, assisting you in immunizing your own child. But for the children the participation was a spontaneous reaction. They are very involved and closely associated with the leadership of Mahila Milan and BSDF who are now their adopted aunts and uncles.

Many of them hang around these settlements. This was their contribution to the families who have shown them love and affection.

The campaign was over, we had statistics from the forms which our volunteers filled out. We had reached out to 4,12,000 odd households, located approximately 63,000 children below one year. Of these, 51,724 had already been immunized and 11,629 were given cards and taken to the hospital.

The campaign ended with everyone feeling very good about what they had done. Apart from the fact that children have received immunization, several other gains were seen to have been made:

* In almost every slum settlement, there was evidence that the campaign was viewed as their own, and the leadership had personally visited the health center and met the doctor and planned the vaccination... something which had not occurred before. This was very valuable from the point of view of mutual accountability. If a service had to be effective, it had to be administered and it had to be utilized.

* It provided the group with "proof" of its effective communication skills. Those who are the targets of communication can and should participate in the creation and execution of the communication process ... especially if the process demanded a change of attitudes and changes in behavior. Our involvement proved to us not only that such a concept could be executed but also that it could be successful and cost effective.

* It further illustrated the effectiveness of multiple involvement. We have always sought to ensure that people participate centrally in development processes. To ensure that this participation is not notional. What is notional? That people are not involved to get a task done... that their involvement is not situational, it instead draws them into considering their need, and linking the focus of the present "program" to that larger alternative.

To that end, this campaign has demonstrated to all of us, that communities can and do have a vital role. The space for this role has to be made both by people and the state. That this can be built upon and over a period of time routinised.

* The challenge ahead of us now is how to build on this success?

How to ensure that this small gain is not lost or forgotten. How to communicate this possibility to other people like ourselves in other cities and towns. And most important not to forget ourselves what we are capable of doing.

It is March 1991 when we sit to write this story. We have made a proposal to the Municipal Commissioner of Bombay. In that proposal we have tried to build on this process by including not only measles but also all other immunizations. We are translating this story in many other languages and circulating it to everyone we know of who can either enjoy reading it, use it or learn from it. We are also sending this to the State administration, the Central government departments and other voluntary organizations who can either promote this kind of process, or if they wish, use the core group which facilitated this process to trigger similar participation in other cities.

