

## Proposals for a pilot project to promote the integration of the hanseniasis patient into society

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**SUMMARY** — After a year-long study of the Baum region in the Brazilian state of São Paulo, the author found 8 basic and interdependent obstacles and comment which hamper the integration of the hanseniasis patient into society. These obstacles are:

1. The lack of a central authority to control integration activities in the region.
2. The lack of basic dogmas and guidelines on which to build a rehabilitation program.
3. The inadequate use of educational resources.
4. The lack of integration of hanseniasis work in the general medical care system.
5. The low quality of basic medical care for the hanseniasis patients.
6. The lack of socio-economic support systems for the hanseniasis patient in his community.
7. The large number of patients in Lauro de Souza Lima (the area's dermatological hospital) interned for non-justifiable reasons.
8. The presence of a growing settlement of hanseniasis patients on the outskirts of Lauro de Souza Lima.
9. Some comments on the structure and function of the pilot project.

Each of these obstacles is briefly discussed and suggestions are then given for a coordinated program to overcome them.

Termos índice: Hanseniase. Integração. Reabilitação. Hospitais. Assistência social.

Key words: Hanseniasis. Integration. Rehabilitation. Hospitals. Social work.

For many years, authorities have been speaking of the need to make of hanseniasis "a disease like any other"; the need to "normalize" the life of the hanseniasis patient as much as possible by promoting his integration into society. These are certainly necessary

goals, but they are goals very difficult to achieve. We face many obstacles and we lack concrete plans and experience to guide our efforts. With this in mind, a number of interested organizations \*\* decided to study the problem in detail in a selected area. \*\*\*

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(\*\*\*) The pilot area selected was the "Seventh Administrative Region of the State of São Paulo" or the "Bauru Region" as it is sometimes called. The region includes 38 municipalities. The seat of the region is Bauru, a city of approximately 150,000 inhabitants. The area has one government dermatological hospital (Lauro de Souza Lima) with some 525 patients. Treatment for the region's 1250 registered outpatients is the responsibility of the government sponsored health centers in each town.

Based on the results of this study, these organizations hoped to come up with a plan of action which could be applied to this pilot area.

What was learned in the implementation of this plan could then

perhaps be applied to other areas of the world with similar situations. In the following pages we will briefly note this plan of action and the obstacles it was designed to help overcome.

## OBSTACLES AND SUGGESTED SOLUTIONS

### OBSTACLE 1.

#### THE LACK OF A CENTRAL AUTHORITY TO CONTROL INTEGRATION ACTIVITIES IN THE REGION:

The integration of hanseniasis services into the general health care system of the state was a courageous and necessary step. Our goals now should be to solidify the positions gained and extend the advance into new territory. This however will not be an easy task, for the obstacles in front of us are numerous, complex, and durable. To overcome them we need a concrete plan, an efficient use of resources, and a leader with the knowledge, interest, and authority necessary to direct the multiple activities required.

Ironically, the present horizontal system and divided authority bequeathed to the region by integration have in many ways become obstacles themselves to further integration and the improvement of basic care for hanseniasis patients. This is due to the fact that while the major portion of "know-how" and supportive equipment in hanseniasis work is concentrated in Hospital Lauro de Souza Lima under one authority, the major responsibility for the care and control of the hanseniasis patient rests with the health centers under another authority. The key to the resolution of the social

problems of hanseniasis patients rests with yet a third authority, the Promoção Social. Cooperation between these three authorities of course does exist, but not nearly on the scale that is needed to bring about the radical changes in hanseniasis work which we hope to see.

In order to bring about these changes, this cooperation should be increased and even formalized, at least on a temporary basis. We must not fool ourselves. The concept of "integration" has been delivered but it still must be guided by a wise and strong hand until it can walk on its own. Our first suggestion is to designate the hand that could be the guiding force.

*It is therefore suggested:*

#### 1.1

That the administrative region of Bauru be officially designated as a pilot area for testing new concepts in hanseniasis control and rehabilitation.

#### 1.2

That a project director be appointed and given the necessary authority to guide and coordinate the diverse activities needed to breakdown the barriers which separate the hanseniasis patient from a normal life in his community. This director would be responsible to

the "Commission for the Coordination of Hanseniasis Activities" in São Paulo (\*).

### 1.3

That an "Executive Committee" be formed at the regional level, of authorities whose support is critical to the success of the pilot project. This committee could provide advice to the project director and help to achieve mutually accepted goals with the resources under their command. While this committee can change as circumstances change, it is suggested that the following persons form its core:

#### 1.3.1

Director of Hospital Lauro de Souza Lima and the "Caixa Beneficente of Aimorés" (\*\*)

#### 1.3.2

Director of regional health centers.

#### 1.3.3

Representative of the department of promoção social in the region.

## OBSTACLE 2.

### THE LACK OF BASIC DOGMAS AND GUIDELINES TO BUILD UPON:

Scientific language is one of qualifiers — of "if's", "but's", and "may-be's". This is particularly true in the case of hanseniasis, a disease with many unknowns yet to be clarified. For examples : When can a patient be

considered non-contagious? When is he cured? When can he be given clearance to work and in what types of jobs? Should employers be encouraged to dismiss workers who are positive? If so, for how long? If not, what should be said to the employer? What types of precautions should be taken to protect other workers? Should BCG be promoted as an effective vaccine against hanseniasis? Who has resistance against the disease? Which contacts should be controlled? How long should they be controlled? When should patients be sent to special dermatological hospitals? When should it be insisted that they receive their treatment in general hospitals or general social institutions?

Specialists disagree among themselves on the answers to these and other important questions. This disagreement is understandable but very unfortunate for the doctor or rehabilitation worker whose job is to bring about a radical change in the relationship between the hanseniasis patient and society. Revolutions are brought about by people who know what to do and believe in what they are doing. Belief is generated more by slogans, simple guidelines, and example than by subtleties. This being the case, we must develop a core of official dogmas, guidelines, and goals regarding hanseniasis. These must answer the important questions which will be asked over and over during the rehabilitation process and motivate persons to take action. These answers should be as simple as possible, emphasizing the normal rather than the abnormal, the positive rather than the negative. They should be backed up with evidence which is

(\*) This commission counsels the secretary of health of the state in matters relative to Hansen's disease.

(\*\*) Years ago "Caixa Beneficente's" were set up in the state sanatoria to serve as channels for private donations to the sanatoria, to coordinate social activities for the interned patients, and to defend the rights of the same. "Ahnorés" was the old name of Hospital Lauro de Souza Lima.

easily understandable. And most important, they should be backed up by the actions and examples of those who teach them.

*It is therefore suggested:*

### 2.1

That the project director call together a team of experts in order to decide on the basic dogmas, guidelines, and policies which will serve as norms for the pilot project in the region.

### 2.2

That this "Normative and Technical Committee" consist of the dermatologists of Lauro de Souza Lima, the dermatology inspector for the region, and any other figures whose expertise would be useful to the committee.

### 2.3

That the norms resulting from this committee's work be submitted for approval to the "Commission for the Coordination of Hanseniasis Activities" in São Paulo and to the "Project's Executive Committee".

## OBSTACLE 3.

### THE INADEQUATE USE OF EDUCATIONAL RESOURCES :

Once we decide what we want to teach others about hanseniasis, we must then organize ourselves to teach. The importance of education as a weapon in overcoming the barriers which separate the patient from a normal life in his community can hardly be overestimated. Education is the force that motivates; it is the force which explains "how". Every person involved in any way in hanseniasis

work should be an educator. These at times however, will need the support and training of expert specialists. As we have noted, the majority of the hanseniasis specialists in the region are concentrated in the Hospital Lauro de Souza Lima, while the majority of barriers which need to be broken down are in the community. Ties between the specialist and the community must be increased. These specialists must become more mobile, more out-reaching.

Using the hospital as their base, there are basically three types of education programs which should be developed. The first of these is a *general education program*. The more integration increases, the more the patient is dependent on the resources and acceptance of the community to solve his problems. Many community organizations, including medical, are reluctant to provide services to patients because of antiquated ideas about the disease. They need to be brought up to date and motivated. While many apprehensions can be dispelled by lay hanseniasis workers, some persons insist on listening only to medical specialists. For example, it is perfectly natural that the head of an industry or a church would want to talk with an expert in hanseniasis before admitting a patient for the first time to its organization. The specialists in the hospital must be prepared to provide such counsel and assurance.

Another type of education program which is absolutely necessary is the *technical training program*. Motivation is not always enough. Doctors, social workers, and paramedicals must be taught *how to care* for the leprosy patient in his community. They need to know how to avoid physical and social problems connected with the disease and what to do once these problems occur. Again, the hospital is

*Pilot project to integrate hanseniasis*

the natural base for such an education program during this transition period.

A third type of education program which is needed is one directed to other hanseniasis programs and workers in other parts of the state, Brazil, and the world. *This divulgation program* should have as its objective the spreading of information about the Bauru project — its goals and methods. Once the project begins to function, the hospital and the health centers involved in it should develop special training programs for the benefit of outside visitors.

*It is therefore suggested:*

3.1

That a "coordinator of resources in Hospital Lauro de Souza Lima" be appointed. Probably one of the hospital dermatologists would be best fit for this job.

3.2

That it be the responsibility of this leader to serve as an intermediary between the educational requests from the outside and the educational resources inside the hospital (dermatologists, surgeons, P.T., O.T., etc.). In other words, this leader would consider each request for help and then assign personnel within the hospital to fill the request.

3.3

That when possible, education activities be held within the hospital in groups and on certain designated days of the month.

3.4

That otherwise, specialists should go to the community to meet with groups

or individuals and deal with the particular need. (Sometimes telephone calls will suffice).

3.5

That these mobile educators should be granted time from their regular hospital duties and backup support from the hospital such as gasoline costs.

3.6

That since most educational requests will call for the expertise of dermatologists, these should alternate the times when they are available so as to create as few problems as possible with their normal schedules. Since there are four hospital dermatologists, arrangements could be made so that one would be available for duty only once every four months. Within these months, certain days could be set aside for teaching and traveling.

3.7

That efforts be made to advertise the "new" hanseniasis and the pilot project activities. Newsletters, papers, radio, television — all should be *used* when possible. What is said will of course have to be carefully considered. It is also suggested that the hospital organize national and international conferences from time to time.

OBSTACLE 4.

THE LACK OF INTEGRATION OF  
HANSENIASIS WORK IN THE  
GENERAL MEDICAL-CARE  
SYSTEM:

Much work has already been done to integrate hanseniasis services into the general medical-care system but much

more needs to be accomplished. In the region of Bauru only 44% of the health centers are integrated in the sense that hanseniasis care is given directly by one of the local health center doctors. In the rest, it is the area inspector who provides the treatment on certain days. Where health centers are large enough to have separate dermatology departments, there are further signs of lack of integration. Having separate entrances, these departments are largely separate from the activities of the rest of the health center. One hears complaints of discrimination in the distribution of common resources such as vehicles and sanitary visitors. Too, some doctors of other specialties in the health centers are reluctant to treat hanseniasis patients when these are in need of their services. Outside the health centers, some medical organizations such as Funrural, INPS, general and specialized hospitals do not accept hanseniasis patients for treatment of other problems even though these have a need and a right to their services. Instead, the patient is referred to the health center or to Lauro de Souza Lima.

There are a number of reasons which could be given to explain this lack of integration. First, there is *fear*. There are many medical workers who are unduly afraid of contact with patients. Others, who may not be afraid themselves, are anxious about the reactions of other clients were they to treat hanseniasis patients. Second, there is the *lack of know-how*. Some medical workers do not wish to treat hanseniasis patients because they feel that they lack the necessary background in the disease to handle its complications. Third, there is the excuse of *poor pay*. Government doctors are poorly paid. Many compensate for this by working far fewer hours than their contracts stipulate. They are therefore free to

spend more time in more lucrative private practices. Any thing which would bind them longer to their government jobs (like treating hanseniasis patients) would be unwanted responsibilities. On the other hand, those working in private practices are reluctant to accept hanseniasis patients because these are generally poor without the ability to pay. A fourth reason for the lack of integration is that there are *alternatives*. Since a dermatological hospital exists, why not send the patient there where he can get specialized treatment? Why insist on sending him to a general hospital? A fifth reason is that *integration has never been tried*. Some organizations or institutions have never been confronted with the problem of whether or not they should accept hanseniasis patients. This state of affairs may be due to a lack of need or to pessimistic attitudes of the patient or of the hanseniasis worker who don't care to try.

Whatever the reason, it is extremely important that the integration of hanseniasis work in the general medical system be completed. For the patient to remain in his community he must be treated in his community. For hanseniasis to become "a disease like any other", it must be treated like any other. If the medical profession doesn't take the lead in this, than how can one expect lay persons to follow?

*It is therefore suggested:*

#### 4.1

That a concerted effort be mounted to integrate all of the medical institutions in the region.

#### 4.2

That a "coordinator of the project's medical activities" be appointed.

Among his duties would be the coordination of this integration effort.

4.3

That he be backed up in his efforts by the director of regional health centers, the education teams mentioned in the last section, the area dermatological inspector, and by the chiefs of the local health centers.

4.4

That the first step be to further integrate the health centers — turning over more responsibility to the heads of the local health centers for the primary care of the patients, making more use of other health center doctors for treatment of the patients other problems, and breaking down any unnecessary discriminatory barriers which exist in the health centers.

4.5

That simultaneously, efforts should be made to increase the integration of other medical institutions which serve the region and its communities. It is suggested that when a situation arises in which a hanseniasis patient needs treatment for a particular medical problem, that this patient be sent to the nearest institution which offers possibilities for the care of this problem. In this way, the issue will be forced.

4.6

That if the institution or specialist refuses to accept the patient, then the reasons for this refusal should be noted. We should then do all in our power to overcome the obstacles mentioned.

4.7

That a chart be kept of the progress being made in this area.

OBSTACLE 5.

THE LOW QUALITY OF BASIC MEDICAL CARE FOR THE HANSENIASIS PATIENT:

The integration of hanseniasis work in the general medical-care system is just decoration unless the integrated services meet the basic needs of the patient. In other words, integrated hanseniasis work must attain a certain level of quality to be effective. "Quality" however is a relative concept very difficult to define. In comparison with many other hanseniasis programs in Brazil and in the world, the quality of the program in the Bauru Region might be seen to be high. Yet there are many improvements which could and should be made. First let us look at *case-finding*.

It is difficult to overemphasize the desirability of finding and treating hanseniasis patients at the earliest possible stage. Early detection and treatment lower the risk of the spread of the disease in the community and increase the chances for the patient's cure without complications. Case-finding activities should therefore be as aggressive as resources allow. The most productive type of case-finding activity, is the control of the patient and his household contacts. In Bauru "control" is defined as the revision of the patient and his contact at least once a year. Judged by this standard, "patient control" in the region is very good, reaching a level of 90% in 1974. The control of contacts is less effective. It is difficult to judge by how much however, because there seem to be differing definitions as to just what contacts should be controlled. Some health centers appear to control *all* of the persons who live in the household of the patient regardless of the Mitsuda reaction of the contact or the form of

the patient; others control only the contacts of lepromatous or borderline cases ; others, only those who have Mitsuda negative responses. Whatever the definition, signs are that "contact control" is not as good as it should be. Official statistics show that 549 out of 2173 contacts (25%) were out of control in 1974. (In 1973 however, 56% were out of control) . The number out of control in 1974 is probably higher than these statistics indicate. Interviewing samples showed that 21% of the addresses of patients obtained in the health centers incorrect thus hampering effective control (50% in Bauru). Of those patients who were found and interviewed it was noted that the number of persons living with them was usually higher than that indicated in the contact records of the health center. If the results of the sample were to be extended to the region as a whole, approximately 960 persons who actually live with the patient have never been registered as contacts. (Considering the different procedures in registering contacts, this statistic should only be relied on as an indicator of a tendency). Other types of case-finding activities in the region do not seem to be undertaken. School or mass surveys are not attempted, nor are dermatological exams required before the issuance of health cards. Neither do there seem to be organized community education campaigns to make the public aware of the first signs of the disease and to reduce its stigma so that the spontaneous presentation of patients is stimulated. Initial tabulations from a community study indicate a low knowledge level in relation to hanseniasis.

Another area in which there is room for improvement is in the *preventive care* given to patients. The health centers are especially weak in this area but the hospital is not too far ahead. The patient has as much need

of education about the disease and of support in preventing incapacities as he does of sulphones. Our survey indicates that this education and support is not being given at the level it should be. For example, the knowledge of the patient about his disease is very low. On a basic hanseniasis knowledge test, hospital patients scored on the average 56% correct; those in the settlement of hanseniasis patients outside the hospital, 52%; while other outpatients in the seven samples municipalities scored on the average 41%. In the hospital, 12% of the patients reporting insensibility in their feet were wearing shoes with nails and no modifications when they were being interviewed. Outside the hospital, this was true for 21% of the patients. Precautions taken by patients to protect their insensible feet and hands were minimal. In the hospital, patients on the average mentioned 2.0 specific precautions (such precautions as "washing" or "wearing shoes" were admitted even though obvious). Outside the hospital the average was 1.3. As for protecting insensitive hands, the hospital patient noted an average of 1.7 precautions, while those outside the hospital noted 0.9. When the patient in the community does develop plantar ulcers or other complications because of his disease, the health center is usually not equipped to care for them. Patients who should be cared for in the health center are therefore unnecessarily sent to the hospital.

To increase the quality of basic care for the hanseniasis patient both in the hospital and in the health center, we will in some cases need to *recruit more personnel and increase other types of resources*. More paramedicals and transportation are especially needed in the larger dermatological departments. We will need more *planning*: goal setting, scheduling, and evaluation activities so that the resources we have



are stretched to their highest efficiency level. And perhaps most important of all, we need to substantially *increase the training and motivation of the hanseniasis worker* so that he takes more interest and initiative in his work. The unmotivated or untrained worker is more often an obstacle than an asset.

*It is therefore suggested: (\*)*

### 5.1

That our efforts for improving the basic care of the hanseniasis patient in the health center be based on the Venezuelan model. In such a model, paramedicals are entrusted with major responsibilities in the maintenance and development of the hanseniasis program. Visiting the patient in his home at least once a month, they give injections, educate the patient and his family about the disease, and teach the patient how to care for insensitive, weakened, or stiff-jointed hands and feet. These paramedicals take note of the changes in the household composition of the patient and help in the control of the patient's contacts. They are also very effective in mass surveys, education programs, or vaccination campaigns. When problems arise which are beyond their competence, these problems are referred to doctors, social workers, or other specialists. Well trained, organized, and motivated, they are an efficient and powerful weapon against the disease. It is suggested that a similar approach with modifications be used to combat the disease in the region, and that one of the directors of the Venezuelan program be invited to help set it up.

### 5.2

That the municipalities of Bauru and Duartina be designated as pilot centers

for the development of the model program in the treatment of Hansen's disease patients in the health centers. Bauru is a logical choice because 40% of the region's outpatients live in this municipality. Duartina being a much smaller city than Bauru and having less than 20 patients, could serve as a model for cities in the region which don't have specialized dermatology departments in their health centers. The fact that both cities are near Hospital Lauro de Souza Lima will be helpful in the supervision of the program in its initial stages. Once the program begins to function in Bauru and Duartina, it is proposed that it be expanded to other cities in the region. These two municipalities would then be used as training centers for persons from other parts of Brazil.

### 5.3

That the "coordinator of the project's medical activities" be responsible for developing the hanseniasis medical programs in the health centers of the region, starting with Bauru and Duartina.

### 5.4

That a health visitor and six "assistant health visitors" be assigned by the Bauru health center to work in this program. All of them must be willing and able to be highly mobile. Preferably, the assistant should be between 25 and 40 years old, and with at least an elementary education. It is suggested that they work six hours a day and that their salary be in accord with Reference 10 to 12 of the Wages for State Civil Servants. It is also suggested that these assistants *not* be Hansen's disease patients.

(\*) These suggestions are related to the Improvement of the quality of basic care in the health centers. Suggestions for the hospital are included in another section.

5.5

That the municipality of Bauru be divided into four areas. An assistant could be assigned to each area, having approximately 100 patients under his responsibility. These patients would be visited at least once a month and more often than this in special cases. A fifth assistant could be assigned to the health center to deal with patients who prefer not to be visited in their houses. A sixth assistant would substitute for the other assistants when vacationing. All the assistants would also be responsible for health education in the community as well as helping out in mass surveys. The assistant assigned to the health center or another person already working there could learn how to apply plaster casts for plantar ulcers.

5.6

That the health visitor act as the supervisor of the assistants in the Bauru health center.

5.7

That a car and driver be assigned permanently for the use of the supervisor and the assistants of the Bauru health center. Each day they would be left off in their areas at a certain hour and picked up a certain hour. Within their areas they would get around on their own by walking, bicycles or bus. Travel costs should be covered if they are required to use their own or public transportation.

5.8

That one of the health visitors of the Duartina health center be assigned to participate in the pilot program in that city. Unlike the health visitor and assistants of Bauru, he/she would be polyvalent.

5.9

That once the routines and techniques are established in Bauru and Duartina, the program be expanded to other cities of the region. It is suggested that in cities with more than 50 patients an assistant be assigned to work exclusively with Hansen's disease patients. No assistant should have responsibility for more than 100 patients. In cities with less than 50 patients a health visitor could be assigned to take care of the Hansen's disease patients along with his/her other responsibilities.

5.10

That a "coordinator of the project's health education activities" be named to develop and supervise the health education activities of the health visitors and the assistant health visitors connected with the project in the region.

5.11

That the doctors do revisions of patients twice yearly and begin community surveys.

OBSTACLE 6.

THE LACK OF SOCIO-ECONOMIC SUPPORT SYSTEMS FOR THE HANSENIASIS PATIENT IN HIS COMMUNITY:

Hanseniasis is certainly as much a socio-economic problem as a medical one. Because of this, just as we have to give the patient the necessary medical support if we wish him to remain in his community, so must we give him the necessary socio-economic support. Patients like other people need food, clothes, and housing. They require jobs to earn the money to buy these. They need training and place-

ment to get these jobs. When they are unable to work because of sickness, disability, or old age, they need family or social organizations to furnish these basics for them. Added to their material needs, they, like others, have the psychological need of social acceptance and to feel and be useful. During the age in which the segregation of the patient was the chief weapon for dealing with the disease, it was the responsibility of the sanatoria to do what they could to solve the socio-economic problems of the patients within their walls. Now that the emphasis of hanseniasis work has passed to the treatment and control of the patient within his community, this responsibility should also shift to the community. While some steps have been taken to bring this about, the fact of the matter is that the social services offered the patient in his community are inadequate. In some cases, this situation is due to the fact that necessary support systems simply do not exist for anyone; in other cases because those systems which do exist discriminate unnecessarily against the hanseniasis patient. It is therefore our duty to develop and integrate these support systems whenever possible.

The first step needs to be to break down the barriers that separate the patient from receiving necessary aid from existing institutions in or near his community. We need to tap the resources of orphanages, training schools, housing authorities, rehabilitation programs, placement offices, churches, syndicates, industries, commercial establishments, old persons' homes and other types of asylums. To do this will require general and technical education about the disease, and in some cases changes of laws, and financial aid to these institutions.

The second step will be to create necessary supporting agencies or programs where none now exist. For

example, vocational training programs and sheltered workshops for the handicapped are particularly needed in the region. Special programs are needed to help the handicapped start businesses or deal with financial emergencies. We need a voluntary agency to sponsor such programs, to show that they can be effective.

*It is therefore suggested:*

### 6.1

That in each municipality in which hanseniasis is a problem, a representative be appointed to promote the socio-economic rehabilitation and integration of the patient in that municipality. Depending on the situation of each city, this representative could be a government employee or a private one, part-time or full-time, paid or voluntary, social worker or non-social worker. What is important is to have someone assuming the responsibility.

### 6.2

That a "coordinator of the project's socio-economic activities" be named. This person would be responsible for coordinating the development and integration of social programs in the region, beginning with Bauru and Duartina. As opportunities develop, the social program would be expanded to other municipalities in the region.

### 6.3

That the Caixa Beneficente de Aimorés be reformed so that it is more dynamically involved in the socio-economic rehabilitation and integration of the hanseniasis patient. It is suggested that such a reformation include the selection of a board of directors from interested leaders of the hospital, patients, and community; that an *exec-*

utive secretary be hired to develop and control the day to day activities of the organization; and that the major end of the new Caixa be to further the rehabilitation and integration of the hanseniasis patient. Its field of action should not be limited therefore to hospital but should include as well the settlement of hanseniasis patients near the hospital and the community. It is suggested that the main activities of the new Caixa be:

### 6.3.1

*Fund-raising:* If the Caixa is to be effective, it must have funds. Some of these can come from present sources such as agricultural activities. Other sources however must be tapped. Solicitation for funds should be made to regional city governments, voluntary agencies, churches, commercial establishments and industries, the Promoçã\$ Social, and to individuals in the community. Help in raising funds should also be sought from CERPHA and the American Leprosy Missions, at least in the beginning stages of the work.

### 6.3.2

*Vocational Training and Placement:* The Caixa can serve as type of sorting center for hanseniasis patients who desire jobs in the community. It can evaluate the possibilities of patients, help them to obtain training if need be, and work to place them in jobs. In order to carry out these functions, the Caixa will need to seek the close collaboration of the rehabilitation personnel in the hospital and of already established training and placement centers in the city. In some cases, the Caiica could help patients set up their own businesses by persuading volunteers from the community to share their expertise with the patient. The Caixa could also help with low interest loans if its capital were sufficient.

### 6.3.3

*Sheltered Workshops and Home Employment:* Some patients though wanting to work, will not be realistically able to find employment in the normal labor market due to the extent of their physical or mental problems. The Caixa could help these patients and other types of handicapped individuals in the city to work and earn by sponsoring a sheltered workshop and home employment program within the city of Bauru (not at the hospital). The Caixa could teach the handicapped how to make saleable produts, provide the initial material, sell the products, and divide the profits among the handicapped according to the amount of work each had done. Much careful planning will have to be done before such a workshop can exist however.

### 6.3.4

*Education Activities:* The Caixa could also be involved in developing and distributing educational material about hanseniasis both for the community and for the patient.

### 6.3.5

*Other Activities:* The Caixa could be a source of funds for special projects or needs. Often it happens that glasses or prosthesis are needed but the patient hasn't the money to pay for them. Children of patients may need clothes, school books, etc. and the Caixa could help in this. Special machines might be needed by the hospital and the Caixa could perhaps help in this as it has in the past. Patients sometimes need help with legal or housing problems. There too, the Caixa could help.

### 6.4

That a close relationship be developed between the pilot program and

the INPS (\*) Rehabilitation Center scheduled to open in Bauru. INPS with its vast resources, its rehabilitation centers in other parts of Brazil, and the future prospect that almost all Brazilians will be covered by its services, is the key to the future vocational rehabilitation of the hanseniasis patient all over the country. We must do everything to see that the hanseniasis patient is not excluded from their services. It is suggested that we begin by attempting to place several patients in their rehabilitation program in Bauru on a trial basis. The hospital would collaborate in the experiment in whatever way INPS deemed necessary. For example, the hospital could provide training for INPS personnel in how to deal with the special problems of hanseniasis like insensibility; it could furnish direct services in plastic or rehabilitative surgery, physical therapy, occupational therapy, prosthesis manufacturing not only for leprosy patients but for other types of handicapped receiving services from INPS as well. It could also turn over some of its houses in the social part of the hospital for the use of handicapped who have come to the INPS center from out of town. Furthermore, the Caixa could also cooperate by accepting into its sheltered workshop program, handicapped persons who INPS could not place.

## 6.5

That efforts be made at the state level to change laws prejudicial to hanseniasis patients and to seek the cooperation of both federal and state agencies in bringing about the patient's rehabilitation and integration. The

"Commission for the Coordination of Hanseniasis Activities" in São Paulo would probably be the 'best coordinator of such work.

## OBSTACLE 7.

### THE PRESENCE OF LARGE NUMBERS OF PATIENTS INTERNEED IN LAURO DE SOUZA LIMA FOR NON-JUSTIFIABLE REASONS :

When our sample was taken, there were approximately 100 patients interned in Hospital Lauro de Souza Lima under the classification of "social cases". This number however does not represent a true picture of the problem. Of the remaining patients in the institution (approximately 425), it is estimated that at least 40% are actually social cases although given other classifications (\*\*). And perhaps the majority of the rest have insufficient reasons for being interned in a specialized dermatological hospital if the WHO guidelines for such internation were to be strictly followed (\*\* \*).

There are several good reasons for trying to reduce the number of patients in the institution. *First, there is the economic reason.* It has often been stated that it costs 10 times as much money to keep a patient in a hanseniasis institution as to treat him in his home. Money for hanseniasis work is limited and it must be used as efficiently as possible. It is unfair to spend the bulk of this money for the care of a privileged few while the majority go without adequate basic care. *Second, there is the argument of stigma.* The

(\*) INPS is the national social security agency of Brazil.

(\*\*) Estimate based on the review of sample files by the director of medical services at the hospital.

(\*\*\*) The World Health Organization's "Guide for Leprosy Control" recommends that the role of the sanatoria "should be limited to the treatment of cases with acute reactions and other complications, to surgery and physical rehabilitation, and to serving as centers for research and training.

continued existence of large hanseniasis colonies feeds the outdated belief that hanseniasis patients must be separated from society; that the disease is not like others. Such a belief makes the recruitment of professionals difficult and makes life harder for the patient who lives in the community. *Third, the existence of separate hanseniasis institutions hampers integration.* As long as the alternative exists of sending patients to segregated hanseniasis institutions for medical or social care, the patients families and community organizations will continue to do so. Their own resources as well as those of the patient for dealing with the problems will go undeveloped.

Hospital authorities are aware of the need to reduce the number of unjustifiable internations in the institution but a number of tenacious obstacles block their way. *One is the lack or ineffective use of resources.* It has often been stated that hanseniasis is as much a social problem as a medical one. This fact is reflected in the large number of social cases in the institution but not in the number of social workers. There are only four persons working as social workers in the institution while the number of doctors is many times that. Much of the social workers time has to be spent in work which is only tangential to what their true goal should be — the returning of the patient to his community. Another obstacle is *the lack of adequate support systems for the patient on the outside.* This problem was discussed in the last sections. The fact of the matter is that the present medical and social care systems on the outside are not adequate to absorb and treat the patients of the institution. A third obstacle is *the dependence of the institution on cheap hanseniasis patient labour.* Because the institution is large and separated from the normal community of Bauru, patients are needed

to help run the institution. But on the other hand, the institution remains large because these same patients are allowed to stay. Thus we have a vicious circle. A fourth obstacle to reducing the number of social cases in the institution is *the lack of motivation on the part of many patients to ever leave.* Fifty percent of the institution's patients felt that life was better for them inside the institution than outside of it. Fifty-five percent stated that they would not have the necessary resources to leave were they ever discharged. This is understandable since the average total internation time in hanseniasis institutions for the patient in the "social case" category is approximately 15 years. That of the non-social case is 7 years. Many of these patients have thus become institutionalised, having burned behind them their bridges to their families and communities. Since hanseniasis authorities themselves were responsible in a large part for this situation, we cannot throw out these patients now without giving them needed support. We have changed the rules of the game so we must be fair to the patient. For them to return to the outside, they need motivation and acceptable alternatives. It is up to us to help them find these.

*It is therefore suggested:*

### 7.1

*That integrated alternatives be sought for the care of the irrecuperable hanseniasis social case.* There have to be institutions which will care for the hanseniasis social case. The main decision which has to be made is whether such institutions should be specialized in hanseniasis like the leprosaria of the past, or whether they should be integrated institutions which care for other types of disabled as well. For reasons which have already been noted, it is suggested that these be integrated. There are several alternatives for

creating such integrated social care institutions. First, we could integrate the social sections of existing hanseniasis institutions by introducing social cases who are not patients. Second, we could place hanseniasis social cases in already existing non-specialized centers which care for the old, disabled, or unwanted. Third, we could build new centers which would care for all types of social cases, including hanseniasis patients.

In the Bauru Region, probably the best choice would be to build a new center. At present both the quantity and quality of care for the social cases of the region leave much to be desired. A regional social care center, probably best sponsored by the Promoção Social, would fill an important gap. The second best choice would probably be for the Secretary of Health or the Secretary of Promoção Social to enter into agreements with several existing asylums in the region and send hanseniasis patients to these. These selected asylums would have to receive both financial and technical aid were they to accept a large influx of hanseniasis social cases. The alternative of integrating the social section of Lauro de Souza Lima is probably the least inviting of the alternatives. The hospital directors want to get rid of the social part of the institution. If this alternative were chosen, the social section would of course then be permanent. A new administration would have to be set up, and much money spent in remodeling. It would be as easy and as cheap to build a new center. Yet all of the choices are viable. One must be selected if we really want to change the present pattern of caring for hanseniasis social cases.

## 7.2

*That efforts be increased to slow down unnecessary internations in Lau*

*ro de Souza Lima:* It is suggested that the normative committee for the region, mentioned in an earlier section, draw up a list of what it considers to be legitimate criteria for interning patients in the institution. These norms should be mailed to hospitals, health centers, or other organizations which normally send patients to the institution.

Patients however will continue to show up at Lauro de Souza Lima seeking internation for unacceptable reasons, be they social or medical. Much wisdom is needed in dealing with such cases. On the one hand, we need to force the issue so that other alternatives are found for them in the community, in integrated institutions; on the other, we need to be fair to patients who have no other alternative.

It is suggested that *medical cases* be accepted, treated, and returned home. But the matter should not be left there. The hospital should contact the institution or doctor doing the referral (usually the health center), explain the new policies of the hospital, and encourage the institution to seek community based answers to the problem should it occur again. If help is needed in setting up such alternatives, the hospital should be ready to cooperate.

The hospital response to the new *social case* seeking admission is more complicated. The social case cannot be "treated and returned home". He requires long-term care which the institution does not want to have to give. Yet something has to be done to help the social case. It is therefore suggested that he be housed temporarily in a transient part of the institution and that a social worker be dispatched to the patient's community in order to try to resolve the problem there. If these efforts fail, the social case will then have to be interned in the social part

of Lauro de Souza Lima or of some other hanseniasis institution until the time that an acceptable integrated alternative is set-up. (See suggestion 1).

### 7.3

*That efforts be increased to return to the community patients who are now unnecessarily interned in the institution (\*)* It is first suggested that a review be made of all of the patients in the institution and these be rated in a number of scaled categories such as the following:

#### 7.3.1

Medical need for hospitalization (in line with international norms)

#### 7.3.2

Physical resources for living outside the institution (age, deformities, abilities, proneness to reaction, etc.)

#### 7.3.3

Economic resources for living outside (personal income, property, jobs, etc.)

#### 7.3.4

Social resources for living outside (family, friends, social organizations, etc.)

#### 7.3.5

Motivation (desire to live outside, international time, etc.)

Based on the results of these ratings, each patient should then be placed in one of three groups:

a) Patients who need hospitalization for legitimate medical reasons.

b) Patients who are hospitalized for socio-economic reasons with a poor chance of living outside the institution.

c) Patients who are hospitalized for socio-economic reasons with a fair to good chance of living outside the institution.

The institution should then be divided into three sections in order to accommodate these different groups of patients. Each section would have its own distinct goals and orientations.

*The hospital proper:* The goal of this part of the institution should be to treat the patient who needs special medical or physical rehabilitation services unavailable in any institution closer to his community. As soon as the patient's particular problem is reduced to the point in which home treatment is possible, he should be discharged. Entrance into the medical part of the institution should be controlled and social cases living in other sections of the institution should be submitted to the same admission procedures as those coming from outside communities. It is suggested that as possibilities for the integrated treatment of the hanseniasis patient in general hospitals increase, that Lauro de Souza Lima become more of a general hospital itself.

*The asylum:* This part of the institution should provide humane care for social cases now living in the institution who have poor chances of ever leaving. Once established, the number of persons cared for in the asylum should ever be decreasing as death or their incorporation in other social care institutions occur. The asylum is not to be viewed as a permanent reality. It

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(\*) Many of the basics of this part are founded on suggestions of Dr. Diltor Opromolla, the director of medical services of Lauro de Souza Lima.



*Pilot project to integrate hanseniasis*

should therefore not be considered an *acceptable* alternative for new social cases from outside the institution.

*The residences:* The patients who would be placed in this section will be judged to have insufficient medical reasons for internation in the, hospital proper, and insufficient social reasons for internation in the asylum part of the institution. For various reasons however, they do not wish to leave the institution. This section should be the first to go. To get rid of it will require a tightly controlled admission policy, the withdrawal of many of the privileges which make institution life appealing, and most important, the provision of aid so that the patient can begin to construct a new life on the outside.

Although each of these sections have different goals, they will be dependent on the use of common institutional resources to achieve these goals. These resources will have to be organized carefully so that "blurring" (and therefore reverting back to the old type of institution) is kept to a minimum. Until we have a closer estimate of the number of patients who will be cared for in each section, we cannot make more than tentative program and organizational suggestions. But for the moment at least, the following seems viable.

*Administrative organization:*

It is suggested :

a) That clear administrative distinctions be made between the three sections, but not to the extent of creating separate bureaucracies.

b) That symbolic physical barriers be erected between the three areas.

d) That patients' files be separated according to sections.

e) That separate statistics be kept for each section in important matters. This would give us a better idea of patient movement, maintenance cost per day, and future requirements for each section. It would also help us evaluate how we are progressing towards our sectional *goals*.

f) That the movement of patients between the areas be kept to a minimum.

g) That separate regulations be made for each area. For example, recreation activities will be organized for patients in the asylum but not in the ambulatory section. Patients in the ambulatory section would be obligated to take care of their area and devote some time to institutional maintenance work.

h) That paid jobs in the institution be used as incentives to get patients out rather than keep them in the institution.

i) That social cases who receive an income of the minimum salary or more be required to pay a fair amount for their food and shelter. This money could go to the projects of the new Caixa Beneficente.

*Organization of Medical Care and Health Education*

It is suggested :

a) That the director of medical services of Lauro de Souza Lima continue to be responsible for all medical activities within the hospital proper and social section of the institution (i. e. asylum and residences).

b) That a health educator be appointed in the institution. This person, under the supervision of the di-

rector of medical services, would have as his chief responsibilities the development and supervision of health education activities for patients and the development and supervision of health education activities for patients and the non-medical staff of the institution, as well as for outside visitors.

c) That directors be appointed to each of the main sections of the hospital proper (i. e. ambulatory, infirmary wards, rehabilitation center, and surgical center). These directors would be under the supervision of the director of medical services of Lauro de Souza Lima mentioned in item A.

d) That two persons (chaplains, auxiliaries, social workers, or other) be appointed to bear chief responsibility for the health education activities with patients interned in the hospital proper. They would be under the direction of the health educator mentioned in item B. Their work would be organized in such a way that it would lend itself to systematic evaluation.

e) That a director of medical services be appointed for the social part of the institution (i. e. asylum and residences). This director with the help of a medical team would develop a treatment program for patients of the social section similar to that of a health center. The base of such a program would be the ambulatory section of the institution.

f) That three "assistant health visitors" be appointed to carry out health education activities in the social part of the institution. These paramedicals would work closely with the team of doctors in this section and be under the direction of the health educator mentioned in item B. Their program of activities would be similar to those suggested for assistant health visitors working in the health centers.

### *Social Work organization:*

Once a patient has been given a medical discharge from the hospital, the main responsibility for returning him to his community rests with the social worker. In many ways this is the most difficult job in the institution. To be successful in it, the social worker must develop those positive resources of the patient which can be used to link him to the outside. She will have to win the patient's confidence and be highly innovative in her work. She will also have to be highly mobile in order to establish the community based support systems that the patient will require if he/she is to live outside. All of this necessitates a degree of freedom which the social worker does not enjoy right now. To increase this freedom of action it is suggested:

a) That the social workers be relieved of much of their present work which is not directly related to their chief end of returning the patient to his community.

b) That a secretary be assigned to the social work section in order to handle its many bureaucratic demands.

c) That two new social workers be hired. (As the number of social cases in the institution reduces, so will the work load of these extra social workers. It is then suggested that they be assigned to cover the dermatology and tuberculosis areas of the Bauru health center which are also in great need of their services).

Exactly how the work of these six social workers (the two new ones and the four old ones) should best be organized is open to debate for there are many viable alternatives. The advantage of the following structure is that it helps distinguish the three institutional sections from each other. According to this organization:

1 — The chief of the social workers would continue to be the director of specialized services in the institution. It is suggested that together with the social workers much more concrete planning with goal setting and evaluation be done.

2 — Three social workers would be assigned to the hospital proper. The first of these would bear primary responsibility for the initial interviews of incoming patients and for their referral to other agencies if their cases did not warrant hospitalization. The second would be responsible for dealing with the social problems of patients who were interned in the infirmary and surgical wards of the hospital proper. Both of these would have their offices in the ambulatory section of the hospital proper. The third social worker would be located in the rehabilitation center of the hospital and would take care of patients who enter into the rehabilitation program. In cases of absences from the hospital, these three social workers would substitute for each other.

3 — Three social workers would be assigned to the social part of the institution (i. e. the asylum and the residences). The first of these would be in charge of enforcing the rules of the social part of the institution as well as caring for the needs of patients interned in the asylum. The other two social workers assigned to the social part of the institution would be responsible for the patients in the residences. Their primary goal would be to help the patients in this section return to a useful life on the outside. These three social workers would substitute for each other in cases of absences from the institution. Given the primary importance of the integration work in the residences, we should look at it a little more closely.

It is suggested:

a) That the patients in the residences be equally divided among the two social workers in this section.

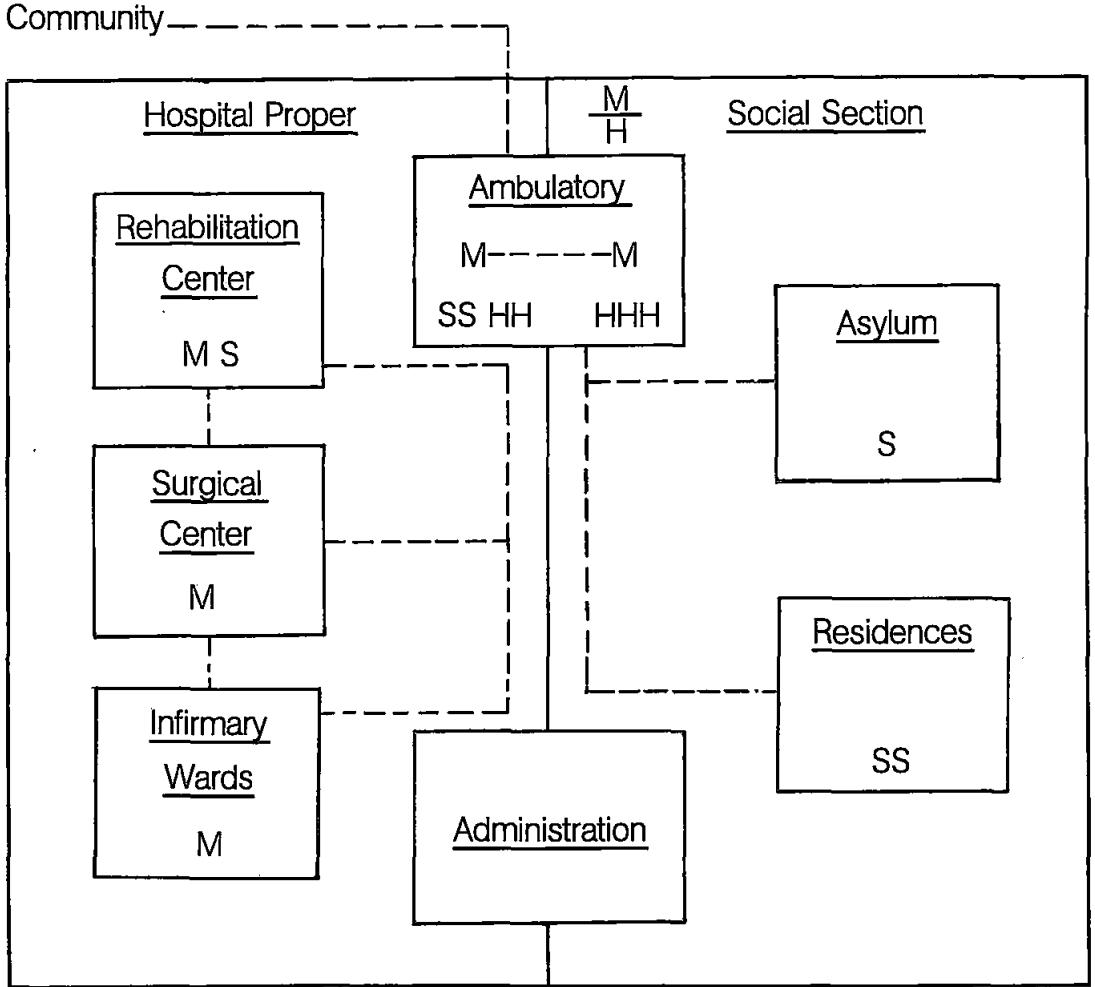
b) That the social workers explain carefully to the patients (in groups and individually) the new policies of the residence section and the reasons for them. Patients' reactions should be solicited and discussed. The patient should be led to feel that while the institution is determined to move towards the future, it will also do its best to help him adjust to the new situation.

c) That the social workers scale the patients in their groups according to their difficulty of rehabilitation. (Such divisions could be based on the questionnaires already mentioned and the social workers own knowledge of each case). They should then begin to rehabilitate the easiest cases first.

d) That the social worker isolate as precisely as possible the real reasons for which each patient refuses to leave the institution. These obstacle should then be dealt with one by one until they are partially or totally overcome.

For example, if the obstacle is the patient's *fear of rejection* because of his disease then frank discussions about stigma and life on the outside should be initiated. Perhaps patients who have successfully integrated could be brought in to help in these. Efforts should be made for the patient to realistically accept and confront his problem with courage and self-esteem intact. If it is a problem of family rejection, the social worker should do all in her power to contact and educate the patient's relatives so as to win their support for the integration of the patient. If it is an *economic problem* which is the obstacle, then there are a number of possibilities for action: with the help of the occupational there-

*Frist*  
 REVISED STRUCTURE OF  
 LAURO DE SOUZA LIMA (\*)



(\*) Only showing the placement of key personnel.

M — Director of medical services of Lauro de Souza Lima

M — Medical directors of sections

H — Health educator of Lauro de Souza Lima

H — Assistant health visitors or other auxiliaries responsible for health education activities in the institution.

S — Social workers

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gist the social worker could evaluate the physical and mental capacity of the patient to do certain jobs. With the help of the new Caixa Beneficente and the new INPS Rehabilitation Center, the patient could be trained and placed. Jobs in the hospital should probably not be given to any more patients, but if they are, they should be reserved only for those patients who agree to live outside the institution and the hanseniasis settlement nearby. The social worker could help in other economic problems such as helping the patient to obtain pensions from INPS or FUNRURAL or in locating housing.

4 — That the social workers of all sections seek always to return the patient to his own community and avoid his settlement in Bauru and most particularly in the hanseniasis settlement near the institution.

5 — That the social workers collaborate very closely with the new Caixa in its beginning stages. The social workers of the institution should in fact play an important part in building the program of the Caixa.

6 — That the "coordinator of the project's socio-economic activities" help develop and coordinate the activities of the social workers in the institution.

OBSTACLE 8.

THE PRESENCE OF A GROWING  
SETTLEMENT ON THE  
OUTSKIRTS OF  
LAURO DE SOUZA LIMA:

Like most hanseniasis institutions in the world, Lauro de Souza Lima has a growing settlement of patients on its outskirts. At present there are approximately 85 patients living in the settlement (at last count, no household in the vila was without at least one patient). This number will no doubt grow

as it has in the past. About half of the lots in Vila Santa Terezinha have yet to be sold and interviews with interned patients indicated that 32% of those listed as "social cases" and 13% of those interned for other reasons would probably move to the vila when and if they were given discharges. If such events occur, the hanseniasis patient population of the vila would double.

The presence of such a hanseniasis settlement, like the presence of so many social cases within the institution, clearly demonstrates that our present programs to promote the integration of the hanseniasis patient into society are insufficient. It is not integration to shift the patient from a segregated hanseniasis institution to a segregated hanseniasis settlement. The stigma produced by the segregation remains. Nor does the shift solve the problem of unnecessary dependence of the patient on the institution, although it may reduce this dependence in the short-run. The settlement patient still has strong ties to Lauro de Souza Lima. This can be seen in the facts that the settlement's water supply comes from institution sources; that 94% of the settlement patients have previously been interned in the hospital; that 35% of the settlement patients now have jobs there; that 14% of the patients in the vila are not even registered in the Bauru Health Center *where* they should be but continue to receive treatment in the hospital; that the majority of those who attend church do so in the institution rather than in the community; and that many of the settlement patients continue to use the social and food services of the institution even though they have been discharged. While reaping many benefits from the institution, the settlement patient is outside its authority. And as long as these ties remain, the settlement will grow. While it may not

be too heavy a burden for the institution to bear now, it may be so in the future as Lauro de Souza Lima moves along the road to modernization.

The problem of the hanseniasis settlement is in many ways more difficult to solve than that of the institution's social cases. As we have said, the settlement patient is not under the authority of the hospital and cannot be so easily discharged against his will. Most of the patients in the vila own homes and since they are paying the bills, they have a moral right to live where they feel they would be most comfortable. Moving to another location is not an easy matter for the 21% who either indicated plans or preference for doing so. They must find jobs to replace those they have in the institution or find other means of support. They must sell their houses, but the only buyers are other hanseniasis patients. This therefore does not solve the problem of the vila. Despite these and other obstacles, we must try our best to reduce the number of patients in the vila. Doing nothing will only create more problems for future patients and hospital administrations. At every opportunity, we should try to increase the motivation of the settlement patient to move, to develop ties between the settlement and the community, and to reduce the ties which bind the settlement patient to the institution. As with the social case, we must be firm in our decisions to solve the problem, but we must be just as well.

*It is therefore suggested:*

### 8.1

That the "coordinator of the project's socio-economic activities" be in charge of this part of the project. He would be aided by the social worker

and psychologist of the Bauru health center, each giving one day a week to the work.

## 8.2

That attempts be made to strengthen the *ties* of the settlement with the community of Bauru. Some of the ways in which this could be done are:

### 8.2.1

To extend the city limits of Bauru so that they include the settlement.

### 8.2.2

To seek increased city services for the settlement such as the pavement of streets, water and sanitation services.

### 8.2.3

To clarify the ambiguous legal standing of property owners in the vila.

### 8.2.4

To promote the extension of the city bus lines so that they reach the vila and the hospital.

### 8.2.5

To promote more exchanges between community church groups and other social organizations with the vila.

### 8.2.6

To increase the number of vila patients who work or study in the city.

### 8.2.7

To increase the vila patient's relationship to the Bauru health center.

### 8.2.8

To encourage the sale of property in the vila to non-hanseniasis patients.

### 8.3

That attempts be made to reduce the ties of the settlement with the hospital. Some of the ways in which this can be done are:

#### 8.3.1

For hospital social workers to discourage patients receiving discharges from settling in the vila, and to help them find other alternatives.

#### 8.3.2

For the hospital not to provide employment to patients who insist on living in the vila. (Those who already live in the vila and work in the hospital would have to be excluded from this new policy).

#### 8.3.3

For the hospital not to provide ambulatory treatment (except in emergencies) or social services for the discharged vila patient unless he be referred by the health center.

#### 8.3.4

That much tighter control be exercised over the movement of patients between the vila and the hospital. Patients in the vila should obey the same visiting hours of the hospital as others.

### 8.4

That attempts be made to motivate settlement patients to move to more integrated communities.

#### 8.4.1

*Psychological support:* We must try to overcome the low self-esteem, the demoralization, lack of initiative, and fear of rejection which play a part in drawing and retaining some patients in the hanseniasis settlement. We must

educate the settlement patient about his disease so that he takes care of himself and has a better self-image. We must discuss frankly with him the problem of the settlement — its positive and negative aspects for him, his family, the hospital, and future patients. We should support any attempts he makes to confront the problem of his disease in a healthy manner or to move to a more integrated community. It is suggested that the psychologist, the paramedical, and perhaps some spiritual leaders be mainly responsible for this area of the work. They could meet with the patients individually or in groups.

#### 8.4.2

*Economic support:* For patients to leave the vila, they are going to have to sell their houses and find others in the community. They are also *going* to have to find in many cases, community based means of support. It is suggested that the social worker of the health center and the new Caixa Beneficente help in these areas. (See suggestion on the Caixa in other section). These would establish contact with community organizations such as churches, service organizations, training centers, housing authorities, placement offices, or employers when specific help was needed.

### 8.5

That attempts be made to integrate the settlement. Integration is a two-way street. It can be accomplished by shifting hanseniasis patients to the healthy community or by drawing persons from the normal community to the settlement. The Caixa could help in accomplishing "reverse integration" by advertising in appropriate places when a patient wishes to sell his house. Or efforts could be made to draw a small industry to the area. Such an industry

would create jobs for the patients, occupy unsold lots in the community, and draw "normals" to the area. In all cases, we must be ready to give supportive education about the disease. We must be realistic though. Integrating the settlement will be extremely difficult, not only for reasons of fear of the disease, but also because the infra-structure of the settlement in transportation and utilities leaves much to be desired. Integration will be a long process but it is recommended that we try to speed it along.

## 9. SOME COMMENTS ON THE STRUCTURE AND FUNCTION OF THE PILOT PROJECT

### 9.1

*General Comments:* The principal purpose of the pilot project is to develop existing organizations so that these provide quality medical and social care for the hanseniasis patient in his community and in accordance with international standards. *The purpose is not to replace existing organizations with a new vertical structure.* The director and the coordinators of the pilot program have normative authority only. They do not possess executive authority unless this is "lent" to them by the proper representatives of the organizations they are hoping to help develop. Situations of conflict between the normative and executive structures at the local level can only be resolved by executive authorities at the next highest level.

### 9.2

*Principal Duties of the Primary Elements in the Pilot Project Structure:*

#### 9.2.1

*"Commission for the Coordination of Hanseniasis Activities".*

#### 9.2.1.1

To approve the norms, plans and budget of the pilot project in Bauru.

#### 9.2.1.2

To negotiate with the appropriate executive authorities at the state or federal level to secure the power and resources necessary to the implementation of the plan.

#### 9.2.1.3

To undertake other supportive action at the state, federal and international levels (e. g. revision of laws, contact with government and private organizations as needs arise, divulgation of pilot project).

#### 9.2.1.4

To evaluate the progress being made in the pilot project.

### 9.2.2

*Project Director*

#### 9.2.2.1

To officially represent the pilot project.

#### 9.2.2.2

To preside over the normative executives committees which advise the project.

#### 9.2.2.3

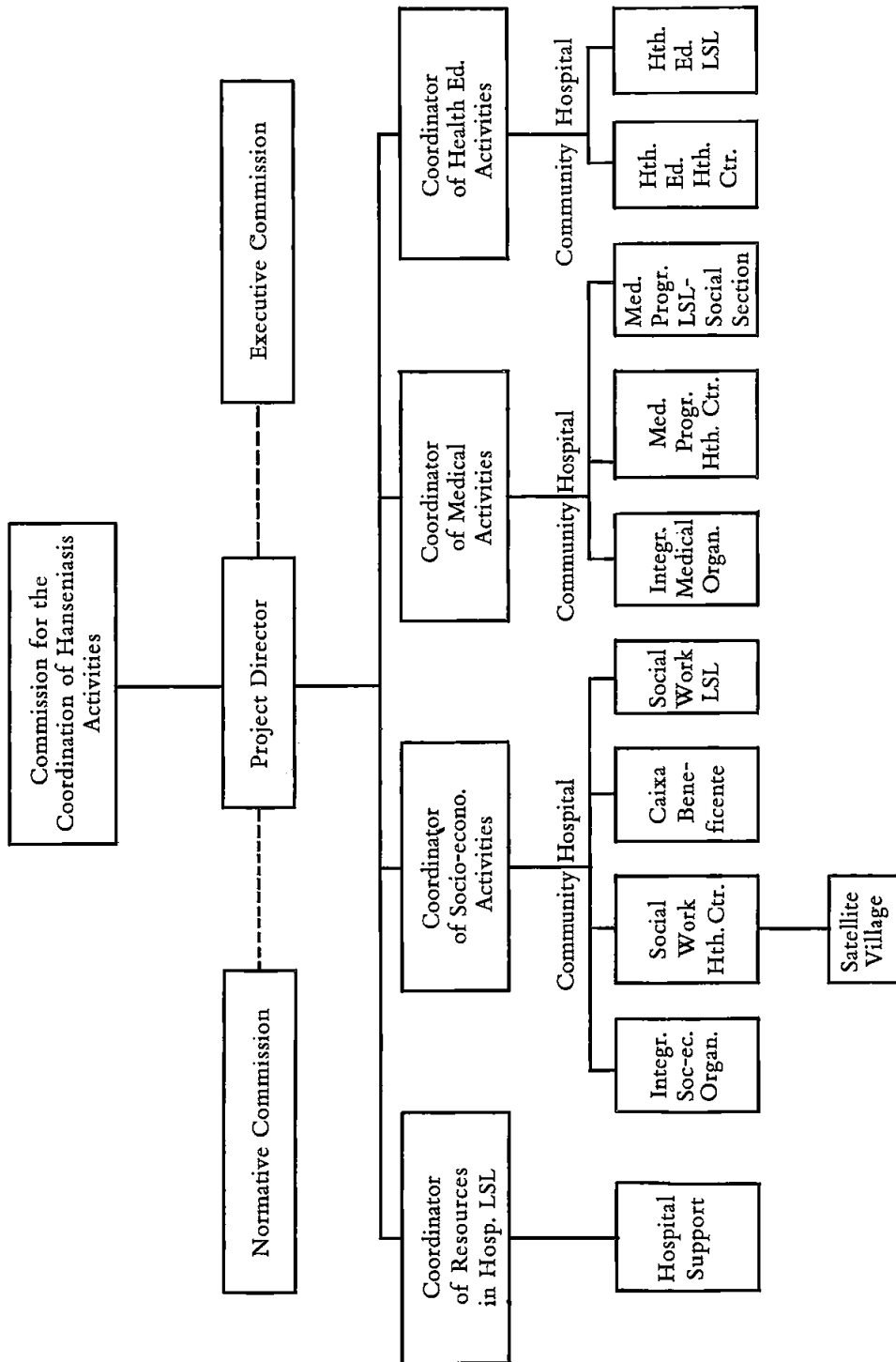
To have primary responsibility for the development of the pilot project in all of its phases (e. g. planning, hiring of personnel, training, supervision, evaluation, expansion, and divulgation).

#### 9.2.2.4

To serve as a link between the pilot project and the "Commission for the Coordination of Hanseniasis Activities" in Sao Paulo.



Organogram of Pilot Project



9.2.3

*"Normative and Technical Commission of the Pilot Project".*

9.2.3.1

To develop the norms of the project.

9.2.3.2

To develop in detail the operational plan of the project.

9.2.3.3

To develop selection criteria and training programs for elements involved in the project.

9.2.3.4

To advise the project director on other matters in which he requests help.

9.2.4

*"Executive Commission of the Pilot Project"*

9.2.4.1

To approve the norms, plans, and budget of the pilot project in Bauru.

9.2.4.2

To confer organizational resources and authority to the director and coordinators of the project so that these may put into effect the project plan.

9.2.4.3

To resolve conflicts between normative and executive authorities at lower levels within their respective organizations.

9.2.5

*Coordinator of the Project's Medical Activities*

9.2.5.1

To supervise the development of medical aspects of the pilot project in the regional health centers, beginning with the health centers of Bauru and Duartina (e. g. epidemiological surveys, treatment schemes, contact control, health education activities, ulcer care, treatment of non-hanseniasis medical problems, issuance of health certificates).

9.2.5.2

To supervise the ambulatory medical program in the social section of Hospital Lauro de Souza Lima.

9.2.5.3

To promote the integration of other organizations in the region which offer general medical services to the general population.

9.2.5.4

To assist the project's coordinator of socio-economic activities in the integration of social and economic organizations in the region.

9.2.5.5

To assist in the training of elements of the pilot project and outside visitors.

9.2.5.6

To participate as a member of the "Normative and Technical Commission" in accordance with the wishes of the project director.

9.2.6

*Coordinator of Resources in Hospital Lauro de Souza Lima.*

9.2.6.1

To coordinate the hospital's educative resources to meet external requests.

#### 9.2.6.2

To assist in the training of personnel of the pilot project and of outside visitors.

#### 9.2.6.3

To participate as a member of the "Normative and Technical Commission" in accordance with the wishes of the project director.

#### 9.2.7

##### *Coordinator of the Project's Health Education Activities*

#### 9.2.7.1

To develop educational programs and materials for the project.

#### 9.2.7.2

To coordinate and supervise the work of the paramedicals involved with the project in the region's health centers and in Hospital Lauro de Souza Lima.

#### 9.2.7.3

To assist in the training of elements of the pilot project and of outside visitors.

#### 9.2.7.4

To participate as a member of the "Normative and Technical Commission" in accordance with the wishes of the project director.

#### 9.2.8

##### *Coordinator of the Project's Socio-Economic Activities*

#### 9.2.8.1

To promote the participation in the project of organizations in the region which provide social or economic assis-

tance to the general population, beginning with Bauru and Duartina (e. g. asylums, churches, schools, orphanages, rehabilitation centers, city governments, community clubs, syndicates, state and federal agencies, placement offices, housing authorities, commercial establishments, and industries).

#### 9.2.8.2

To help develop a new structure and new programs for the "Caixa Beneficente of Aimorés" with the end of promoting the socio-economic rehabilitation of hanseniasis patients (e. g. sheltered workshop, home employment, education activities, resource center).

#### 9.2.8.3

To help develop with the social workers and rehabilitation staff of the hospital, concrete efforts to return unnecessarily hospitalized patients to integrated communities.

#### 9.2.8.4

To help develop with the social worker and psychologist of the Bauru health center, concrete programs to reduce the number of hanseniasis patients living in the hanseniasis settlement on the outskirts of Hospital Lauro de Souza Lima and to integrate the same.

#### 9.2.8.5

To assist in the training of personnel of the pilot project and of outside visitors.

#### 9.2.8.6

To participate as a member of the "Normative and Technical Commission" in accordance with the wishes of the project director.

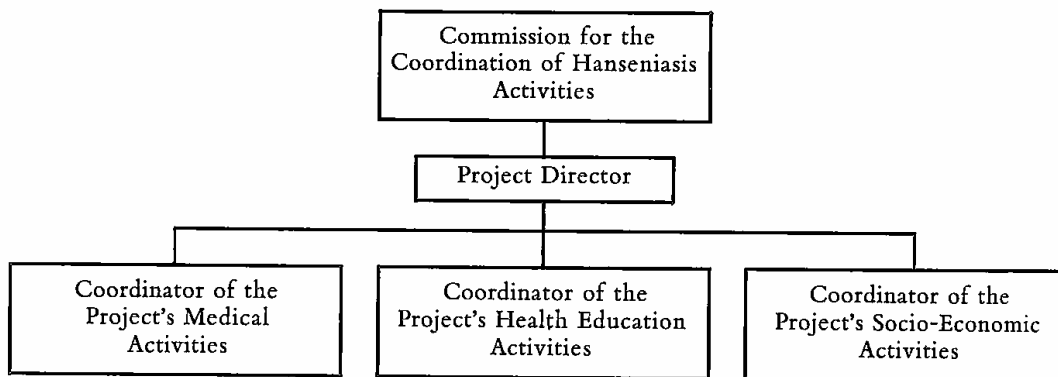
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9.2.9

*Comments:*

If the pilot project proves to be successful, then it is suggested that similar programs be implanted in

other administrative regions of São Paulo and perhaps other states as well. In areas where there are no leprosy or dermatological hospitals, the project's structure would be simplified to the following:



9.2.9.1

The "Commission for the Coordination of Hanseniasis Activities" would issue guidelines for the projects based on the Bauru experience.

9.2.9.2

The project director would be the director of regional health centers or one of his assistants.

9.2.9.3

The coordinator of the project's medical activities would be the region's dermatology inspector.

9.2.9.4

The coordinator of the project's health education activities would be the region's health educator.

9.2.9.5

The coordinator of the project's socio-economic activities would be the region's social worker. In the case that the regional health centers do not have such a person, it would be a representative of Promoção Social.

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