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A WORLD WITHIN A WORLD*

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None can view unsympathetically the social as well as the medical problems presented by the millions stricken by Hansen's disease.** Wholly apart from any scientific studies aimed at a better understanding of the disease itself, the problem of what to do with the afflicted has always been one of the most difficult to solve. If Hansen's disease is transmitted largely by contact, as commonly believed, it must follow that society should protect itself by isolating the sick from the well. But the point of view of the patient must be considered. A great social and economic problem must be met because of the attitude of society the world over toward those who are afflicted, an attitude which marks them and their families as outcasts.

Only a small proportion of the victims of this disease is receiving any kind of care, and very little is being done for those who are dependent upon them. The present discussion is merely an effort to initiate thought toward a practical solution. It is presented with full understanding that the details of any workable plan aimed at adequate care for millions of these ostracized, ill people can be perfected only after long study and experimentation. It is hoped that those who are interested in this problem will contribute, from their own experience, criticisms and suggestions toward an effort to formulate a workable program.

*The Editor of the *Journal*, Dr. H. W. Wade, now interned at Culion, was much interested in this article and considered it a "most admirable and penetrating analysis." He suggested organizing a local project in some country, and mentioned certain readily sterilizable products which might be manufactured.—J. A. D.

**The use in this paper of the term "Hansen's disease" as a substitute for "leprosy" is the responsibility of the author. It is done for these reasons: 1) belief that as in the case of "consumption" a new name is needed for leprosy, 2) to date no better name has been suggested.

What is proposed is a world confederation of communities of persons afflicted with Hansen's disease. These communities may become largely self-supporting, with mutual agreements as to the types of manufacture, farming, animal husbandry and the like to be undertaken by each community. By some method of common coinage and transportation, there would be an equitable distribution of goods. Eventually it should be possible to produce in the colonies everything required excepting a limited number of products, such as certain drugs.

Today there are throughout the world in all leprosaria, governmental and private, less than three per cent of the victims of this disease. Because of the excessive costs, it will not be possible to increase appreciably, by the present method of free subsistence, the percentage in isolation. Almost complete self-support is the only practical method at present by which these people may be afforded a semblance of normal life and given adequate medical care. Increasing the number removed from contact with well people means a reduction of infection in corresponding degree.

Partial self-support, I fear, will scarcely suffice, since a cost of only a few dollars per patient, annually, becomes a staggering sum when it must be given to a vast population, estimated to be anywhere from five to ten millions. If government and private agencies were under the necessity of furnishing only medical care, and spiritual and physical leadership, the financial load would drop into brackets which would not be such an impossible drain on the budgets of health organizations.

One other view of government and mission support should not be overlooked. Such activities are, more or less, at the mercy of severe economic changes, such as those produced by prolonged financial depression or wars. Likewise, they are subject to political changes in government and the possibility of varying interest on the part of those responsible for the work.

Hansen's disease affects the lives, if patients and their dependents are considered, of not fewer than 15,000,000 people. They comprise a greater population than that of many important countries.*

There are difficult problems connected with any form of segregation, whether it be private, governmental, or self-supporting. Many of these cannot be foreseen but must be dealt with as they arise. It may be enlightening, however, to examine some of the more apparent problems as to the practicability of self-support. Some factors to be considered are: a) isolation from families; b) families left uncared for;

* The Encyclopaedia Britannica World Atlas, 1942-43, gives the following general population figures for the countries named: Norway, 2,930,000; Denmark, 3,844,312; Belgium, 8,310,000; Finland, 3,850,000; Commonwealth of the Philippines, 16,000,303; Scotland, 5,040,000; Australia, 7,068,689.

c) life in an abnormal community; d) unwillingness to work; e) partial inability to work because of this disease or coexisting diseases; f) increasing inability to work with advancement of the disease; g) lack of work because of lack of markets.

A) Isolation From Families. This factor probably is one of the most serious obstacles to segregation under any plan. Patients have absconded, under hazardous conditions, that they might return surreptitiously to their families, trusting to the sympathy of neighbors and their ability to dodge the authorities, and hoping to find some means of supporting those who were dependent upon them. The very day this article was being written, I visited a leprosarium where a patient was dying. This particular institution was nearly as ideal as such a place can be; yet this man was calling for his children, begging to be taken to them, screaming that he was in prison and that his children needed him. On the other hand, at Kusatsu, Japan, a voluntary village for sufferers from Hansen's disease sprang up many years ago near a hot spring reputed to possess therapeutic properties. Living conditions there are indescribably squalid, but the afflicted stay on because they can keep their families with them while they seek aid, such as it is, for their malady.

B) Families Left Uncared For. The patient must wish to be in the colony if he is to enter into the routine of the place in such a spirit as to obtain the best results. Since infection as a result of conjugal association is infrequent, it seems more reasonable to permit the husband and wife, even when only one is infected, to go together to the colony than to separate them. If the well member of the partnership should become stricken, the probabilities are that the damage was already done, and he or she would be segregated eventually in any case. Some method should be found to relieve the administration of responsibility for the support of infants born in the colony. In those cases where birth control may not be possible because of religious beliefs, a plan might be worked out with the religious authority representing those beliefs to assume the care of such children.

A special problem is presented by children born prior to the admission of their parent or parents to the isolation community. Present data demonstrate that many of these will become infected. It is important in any complete control method that all contacts, and particularly children, be kept under strictest observation. The children frequently present the most pitiful problems of all. The family and relatives are usually poor. Fear of the disease, as well as financial inability, far too often deter those outside the family circle from assuming responsibility for the care of these children. The simplest solution from all points of view would be to provide for the children a living place near that of

their parents. This arrangement would permit the members of a family to see each other frequently and at the same time not run the risk of being in contact. Those who have visited many leprosaria have reason to believe that some such plan would do possibly more than any other single thing to induce the patient to come to the colony voluntarily, and to make of him a contented and cooperative citizen.

Children who have contracted the disease and who have no parents constitute another problem. In one segregation village at least, the difficulty is dealt with by allowing married patients who have no children of their own to adopt these children when circumstances permit.

C) Life In An Abnormal Community. Exile under any conditions is a hideous prospect for a human being. For the man or woman ill from Hansen's disease, it presents a special horror. He knows that it may be for a lifetime. And when it also means that there is nothing with which to fill the long, empty days except a lonely contemplation of his affliction, his distress becomes almost inconceivable. Some have been known to hide for twenty-five years in holes in the rocks on mountain sides to escape that fate. This unfortunate individual wants treatment, naturally, but often cannot bring himself to pay for it the price demanded of him. He needs a community where he may have his family with him, retain his self-respect by contributing to their support, and enjoy the general conditions of a normal well person.

D) Unwillingness To Work. A great many individuals, not entirely without justification, take the attitude that as society removes their freedom, their living must be provided. No person should be compelled to join the sort of community which has been proposed in this article. He must volunteer as a member, and he will volunteer only if the colony of which he is to become a part is made sufficiently attractive. He must have: tangible evidence of the personal rewards for his toil, enjoyment of a normal life with his wife and so far as possible with his children, good food and clothing, a comfortable home, his church, entertainment, and other things that go with normal existence. He must have reason to believe that his medical care will be the best that can be given. By some pension plan, he should be assured of security for himself and family when he is no longer able to work.

Even this probably will not always be sufficient reason for some to join a self-supporting colony. There should be, through cooperation with the local government, an alternative to his going voluntarily to the community. His illness is, after all, a danger to society, and it is only sensible that it should be protected. If he refuses to volunteer as a citizen of this almost normal community provided for him, he must then go to a regular leprosarium, or if none is available, he will receive no care. If he refuses to work to the extent that he is physically

able (and it scarcely need be stated that nothing more should be permitted), he then is not entitled to membership in a community whose members work for the purpose of obtaining its benefits.

E) Partial Inability To Work Because Of This Disease Or Co-existing Diseases. One difficulty that will instantly present itself to the mind of the practical person is that we are dealing with a population of ill people, many of whom are partially incapacitated. How are they to do a full day's work?

1) It is proposed to provide experts as work directors, machinery, and work animals—assistance which few of the patients enjoyed in normal life.

2) The maimed would be supplied with artificial hands and limbs and given suitable work.

3) Many are able-bodied. The writer has made inquiry wherever he has gone as to the proportion of able-bodied in leprosy institutions. The answer is usually "one half." In many leprosaria only the more severe cases are to be found; therefore, any plan which will encourage *all* the afflicted to present themselves for admission will tend to bring in earlier cases. This would be true especially when the ill are made to understand that the chances of improvement are better if treatment begins early.

4) Permitting the uninfected wife or husband to accompany the ill spouse into the community would be another factor increasing the percentage of those able to be employed.

5) If the plan provides for well children to have their own communities near by, these, too, could become workers as they reached maturity, if they should wish to do so.

6) It must be required of governments or other agencies participating in this plan that they should provide for the individual community the land, buildings, machinery, and work animals without cost and tax exempt. This would be another factor helping to overcome the handicap of a population partially disabled. There should be no charge against their labor for capital account, or interest thereon, rents or taxes. The community should be responsible, however, for the upkeep of such properties.

F) Increasing Inability To Work With Advancement Of The Disease. Many in these communities will be advancing toward a stage of incapability. How are they to be cared for then? Victims of Hansen's disease should be taken off the charity list once and for all. Their disease is misfortune enough; their self-respect, at least, should be left

to them. If they were encouraged and helped to provide for their own physical needs, the large sums of money now going into that ameliorative type of work could be applied to the employment of doctors, agriculturists, manufacturers, religious leaders, and the purchase of medicine. In other words, the funds which have in the past come in large part for houses, food, and clothing could be directed toward the improvement of the patient's mind, spirit, and body.

The United Nations are waging the greatest war in all history that men may be free, that every human being shall have the right and the opportunity to feed, clothe, and house himself; but the individual whom we brand as a "leper" is a human being also, and he is not a criminal. His inalienable right, as well as that of other men, should be the right to the dignity of self-support. He should be paid a daily wage just as is paid an honest workman the world over. That wage should be sufficient to provide him and his family with necessities, and a normally comfortable life, as well as adequate security for old age or total incapacity.

Negatives. One in whom the malady is arrested is often in a less fortunate position than is the active patient. His disease often leaves him maimed, and it is difficult enough for him to earn a living; but to add to his difficulties, well people remain afraid of him, and he finds it almost impossible to secure employment.

There should be in a colony of the sort under consideration an area reserved for the negatives. These should be permitted to have their homes there and should be given the same opportunity to provide for themselves and their families that they enjoyed while they were active patients.

G) Lack Of Work Because Of Lack Of Markets. The lack of work and the lack of markets are inseparable. If it were possible for patients in the community to sell their products, many would work whether compelled to or not. If markets could be created, almost every economic problem connected with segregation could be solved. The market immediately available is offered in the multiplicity of needs of the colonies themselves.

In a world confederation of these communities, with mutual agreement as to the type of manufacture, farming, animal husbandry and the like to be undertaken by each, and some method of common coinage and transportation, there would be an equitable distribution of goods.

It would require only a few outside markets to provide the little legal coinage that would be necessary under the scheme here proposed. Investigation by experienced manufacturers will reveal a sufficient number of commodities that would not be considered dangerous. A simple

illustration is the making of bricks, tiles, and other products that could be removed from the kilns and placed on shipboard by machinery and untouched by hand.

It should be borne in mind that this is a proposal to build a new world. Naturally, careful consideration by experts must be given to the problems that will arise and the methods that must be taken to meet them. The present discussion attempts merely to set forth some reasons why it seems a feasible plan. It will require vision, hard work, ingenuity, and faith, backed by ample financial aid. If successful, it will pay generous dividends.

The author believes that the time will come when through scientific knowledge a better method of the control of Hansen's disease will be found than segregation. The social and economic problems presented by this disease, however, will not be solved until the public, through education, is made to accept a more reasonable attitude toward the patient. So long as we deny him the right to a market for the products of his hands some such plan as the one suggested in this paper seems desirable.