# Swedish International Development Authority (SIDA)

# Evaluation Study of the Multi-Drug Therapy Program in India

## APPENDICES

April 1994

# Swedish International Development Authority (SIDA)

# Evaluation Study of the Multi-Drug Therapy Program in India

## APPENDICES

April 1994

Queen's University, Kingston, Ontario, Canada K7L 3N6

SWEDISH INTERNATIONAL DEVELOPMENT AUTHORITY
(SIDA)

# EVALUATION STUDY OF THE MULTI-DRUG THERAPY PROGRAM IN INDIA

## TABLE OF CONTENTS

SIDA Terms of Reference

Appendices **Page #**

Individual Reports of Team Members

# SIDA TERMS OF REFERENCE

**1993-11-02**

# EVALUATION OF THE MULTI-DRUG THERAPY PROGRAM IN INDIA

## TERMS OF REFERENCE

### Background

Sweden has been supporting the National Leprosy Eradication Program (NLEP) in India since 1978 and the Multi-Drug Therapy (MDT) Program since its inception in 1981. These programs have been given top priority by the Indian authorities, since leprosy is considered a national health problem. At one time the disease affected some four million people in India, and India is still the country with the highest number of sufferers from the disease, but the incidence is going down and a virtual eradication of the disease may be expected. In the highly endemic areas, 16 out of 1 000 had an active infection, but this has been brought down to less that a tenth. MDT, which replaced the original long term Dapsone medication, is supposed to be one of the reasons for this improvement coupled with an effective control mechanism.

The original agreement between Sweden and India has been renewed on two occasions and was extended to terminate in March 1994. The SIDA supported program has reached 19 districts and has been channelled through WHO. (During one period the support was channelled through UNICEF in three districts). The MDT program is now being extended to all districts with endemic leprosy, and the World Bank plans to enter in as a major contributor.

Several reviews have been carried out (1987, 1989 and 1991). Although the epidemiological effects on the whole have been excellent, there are still questions about the MDT and drug efficiency, side effects, the organizational set up of the program in relation the Primary Health care structure, its social impact and the situation of the leprosy cases medically cured. The evaluation may provide answers to some of these questions.

### Reasons for the Evaluation

The Multi-Drug Therapy program is important by its magnitude, by its addressing of a national priority and by being the first of its kind in India, which motivates an extensive evaluation. There is a wealth of experience and information within the NLEP, which needs to be summed up, analyzed and passed on to those continuing the control program or with services to leprosy affected.

## Scope and Focus of the Evaluation

The evaluation shall comprise but not necessarily be limited to the following aspects:

- the epidemiological and public health impact of the Multi-Drug Therapy program related to control and eradication of leprosy.
- the utilization of funds and the cost-efficiency of the program
- the infrastructure and logistics of the Swedish program and how it may be adapted to the epidemiological changes in each area in relation to the PHC structure.
- the quality of drugs and their handling as well as side effects and their treatment
- the social effects of the NLEP with respect to attitudes among the public and with respect to community participation in the program.
- the disability index, according to the guidelines of WHO, eg. the relationship between newly detected cases and the ones with disability among those, and the prevention of the dehabilitation of new cases in the future as well as the possibilities to rehabilitate those physically and socially disabled.

The lesson to be learned from the NLEP for the future operation of the program. Clear recommendations should be made on the aspects of the program. including possible other donors for future financing.

## Methodology, Evaluation Team and Time Plan

The evaluators shall review agreements, national plans and reports. Documentation from similar projects like those of Danida Assisted National Leprosy Eradication Program (DANLEP) shall be studied. Interviews shall be made with the respective leprosy officers on State and District levels as well as the leprosy consultants belonging to the project. Interviews shall also be made with field workers as well as examination of a sample from the target group in at least three districts. (The districts shall be selected to be representative of the leprosy situation and of the socio-economic position). This examination may be complemented by a sample survey to test the reliability of the epidemiological data furnished and by a laboratory control of the drugs used.

The evaluation team will comprise expertise within the following fields:

- leprology, microbiology, pharmacology;
- epidemiology, public and community heath;
- evaluation of health and social projects;
- development co-operation in the health sector and in PHC; and
- disabilities in leprosy and rehabilitation.

Team members will be required to possess a solid experience and knowledge of India, as India is a country with special characteristics with regard to the problem described.

The team leader will be responsible for contacts between SIDA and SIDA/DCO and the team for practical purposes, distributing material, communicating questions and further requests, organising meetings for the mission, etc. The team leader will also compile the report from the individual contributions and be responsible for the final report in accordance with the SIDA guidelines.

The time plan will be as follows:

The evaluation will be carried out between November 1993 and February 1994. A desk study will proceed the mission to India, which will take place in January - February 1994, during four weeks.

## Reporting

A summary report shall be presented to the SIDA/DCO and authorities concerned in New Delhi before the mission leaves India. The final report (following the model specified in Reports on SIDA Evaluation Studies - A Standardized Format) shall be submitted to SIDA, Stockholm not later than 15 March 1994. The final report shall be forwarded to SIDA in five copies and shall be typed on an IBM-compative word processor in MS Word and be accompanied by a diskette.

The Team leader, together with the Swedish team member, shall present the findings and results of the evaluation at a seminar to be held at SIDA, as part of their assignment.

# Appendix - 1 (a)

## SIDA Supported Districts and Operational Data MDT
December 1993

| SR. NO. | DISTRICT | POPULATION ( 1991 Census ) | MDT START DATE | FINANCIAL SUPPORT (Years) | NO. OF CASES BEFORE MDT | | | % OF MB CASES | NO. OF NEW CASES DETECTED | | | % OF MB CASES |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | MB | PB | Total | | MB | PB | Total | |
| 1 | Krishna | 3693179 | 10/1987 | 7 | 6541 | 15404 | 21945 | 29.81 | 5449 | 26973 | 32422 | 16.81 |
| 2 | Vizianagaram | 2110136 | 1/1983 | 8 | 5368 | 18275 | 23643 | 22.70 | 6172 | 23805 | 29977 | 20.59 |
| 3 | Srikakulam | 2321126 | 1/1983 | 8 | 4474 | 26266 | 30740 | 14.55 | 6195 | 18258 | 24453 | 25.33 |
| 4 | Vishakhapatanam | 3272110 | 1/1986 | 5 | 3899 | 20256 | 24155 | 16.14 | 4168 | 21709 | 25877 | 16.11 |
| 5 | Deogarh | 918233 | 1/1985 | 9 | 2483 | 5179 | 7662 | 32.41 | 5312 | 6406 | 11718 | 45.33 |
| 6 | Baroda | 3194692 | 6/1984 | 8 | 4823 | 7152 | 11975 | 40.28 | 5043 | 11107 | 16150 | 31.23 |
| 7 | Belgaum | 3583606 | 4/1986 | 8 | 2839 | 7608 | 10447 | 27.18 | 3156 | 12458 | 15614 | 20.21 |
| 8 | Dharwar | 3503150 | 4/1986 | 8 | 3819 | 9221 | 13040 | 29.29 | 5506 | 14490 | 19996 | 27.54 |
| 9 | Amaravati | 2008568 | 2/1985 | 8 | 1988 | 7316 | 9304 | 21.37 | 2300 | 28017 | 30317 | 7.59 |
| 10 | Wardha | 1065589 | 10/1981 | 8 | 2107 | 6866 | 8973 | 23.48 | 3208 | 29309 | 32517 | 9.87 |
| 11 | Chandrapur | 1768958 | 11/1987 | 6 | 2496 | 14725 | 17221 | 14.49 | 3095 | 28737 | 31832 | 9.72 |
| 12 | Bombay | 9909847 | 9/1992 | 3 | 3838 | 14564 | 18402 | 20.86 | 3806 | 15881 | 19687 | 19.33 |
| 13 | Ganjam | 3158764 | 3/1983 | 8 | 5171 | 31533 | 36704 | 14.09 | 7057 | 42926 | 49983 | 14.12 |
| 14 | Puri | 3590026 | 11/1985 | 5 | 7146 | 24070 | 31216 | 22.89 | 7317 | 23231 | 30548 | 23.95 |
| 15 | North Arcot | 4997666 | 5/1983 | 8 | 10000 | 58351 | 68351 | 14.63 | 7567 | 57620 | 65187 | 11.61 |
| 16 | Tanjavur | 4526701 | 10/1988 | 5 | 6212 | 20484 | 26696 | 23.27 | 3576 | 33586 | 37162 | 9.62 |
| 17 | Chengalpattu | 4620967 | 4/1986 | 6 | 6424 | 37344 | 43768 | 14.68 | 4977 | 66793 | 71770 | 6.93 |
| 18 | Purulia | 2217423 | 9/1982 | 8 | 6251 | 21003 | 27254 | 22.94 | 13792 | 45960 | 59752 | 23.08 |
| 19 | Varanasi | 4798729 | 8/1985 | 9 | 3645 | 11338 | 14983 | 24.33 | 13343 | 18718 | 32061 | 41.62 |
| | TOTAL | 65259470 | | | 89524 | 356955 | 446479 | 20.05 | 111039 | 525984 | 637023 | 17.43 |

# Appendix - 1 (b)

## SIDA Supported Districts and Operational Data MDT
December 1993

| SR. NO. | DISTRICT | TOTAL (OLD + NEW) ACTIVE CASES ON RECORD | | | CASES (OLD + NEW) BROUGHT ON MDT | | | % OF MDT COVERAGE | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | MB | PB | Total | MB | PB | Total | MB | PB | Total |
| 1 | Krishna | 11990 | 42377 | 54367 | 11079 | 36519 | 47598 | 92.40 | 86.18 | 87.55 |
| 2 | Vizianagaram | 11540 | 42080 | 53620 | 9341 | 28610 | 37951 | 80.94 | 67.99 | 70.78 |
| 3 | Srikakulam | 11025 | 48678 | 59703 | 9806 | 24609 | 34415 | 88.94 | 50.55 | 57.64 |
| 4 | Vishakhapatanam | 7265 | 32767 | 40032 | 6890 | 30345 | 37235 | 94.84 | 92.61 | 93.01 |
| 5 | Deogarh | 7795 | 11585 | 19380 | 7795 | 11585 | 19380 | 100.00 | 100.00 | 100.00 |
| 6 | Baroda | 9866 | 18259 | 28125 | 9737 | 17800 | 27537 | 98.69 | 97.49 | 97.91 |
| 7 | Belgaum | 5995 | 20066 | 26061 | 3964 | 16362 | 20326 | 66.12 | 81.54 | 77.99 |
| 8 | Dharwar | 8525 | 23711 | 32236 | 8093 | 23259 | 31352 | 94.93 | 98.09 | 97.26 |
| 9 | Amaravati | 4413 | 37214 | 41627 | 4413 | 37214 | 41627 | 100.00 | 100.00 | 100.00 |
| 10 | Wardha | 5315 | 36175 | 41490 | 4958 | 29308 | 34266 | 93.28 | 81.02 | 82.59 |
| 11 | Chandrapur | 5519 | 43462 | 48981 | 5086 | 39405 | 44491 | 92.15 | 90.67 | 90.83 |
| 12 | Bombay | 7644 | 30449 | 38093 | 7019 | 26257 | 33276 | 91.82 | 86.23 | 87.35 |
| 13 | Ganjam | 11415 | 51017 | 62432 | 10732 | 44432 | 55164 | 94.02 | 87.09 | 88.36 |
| 14 | Puri | 14924 | 46840 | 61764 | 14769 | 37954 | 52723 | 98.96 | 81.03 | 85.36 |
| 15 | North Arcot | 17580 | 115958 | 133538 | 14384 | 67783 | 82167 | 81.82 | 58.45 | 61.53 |
| 16 | Tanjavur | 9671 | 54070 | 63741 | 8669 | 45222 | 53891 | 89.64 | 83.64 | 84.55 |
| 17 | Chengalpattu | 11401 | 104137 | 115538 | 10034 | 69127 | 79161 | 88.01 | 66.38 | 68.52 |
| 18 | Purulia | 20043 | 63954 | 83997 | 18700 | 40635 | 59335 | 93.30 | 63.54 | 70.64 |
| 19 | Varanasi | 16989 | 30056 | 47045 | 16665 | 28959 | 45624 | 98.09 | 96.35 | 96.98 |
| | TOTAL | 198915 | 852855 | 1051770 | 182134 | 655385 | 837519 | 91.56 | 76.85 | 79.63 |

# Appendix - 1 (c)

SIDA Supported Districts and Operational Data MDT
December 1993

| SR. NO. | DISTRICT | CASES COMPLETED MDT | | | % OF CURED CASES | | | TOTAL CASES DISCHARGED SINCE BEGINNING | | | BALANCE OF CASES ON RECORD | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | MB | PB | Total | MB | PB | Total | MB | PB | Total | MB | PB | Total |
| 1 | Krishna | 7230 | 30506 | 37736 | 65.26 | 83.53 | 79.28 | 11513 | 48176 | 59689 | 1597 | 2415 | 4012 |
| 2 | Vizianagaram | 7031 | 24943 | 31974 | 75.27 | 87.18 | 84.25 | 17482 | 65604 | 83086 | 1213 | 1295 | 2508 |
| 3 | Srikakulam | 7588 | 21697 | 29285 | 77.38 | 88.16 | 85.09 | 9585 | 43394 | 52979 | 1084 | 1130 | 2214 |
| 4 | Vishakhapatnam | 5375 | 25896 | 31271 | 78.01 | 85.33 | 83.98 | 7920 | 40457 | 48377 | 656 | 1229 | 1885 |
| 5 | Deoghar | 4794 | 6671 | 11465 | 61.50 | 57.58 | 59.16 | 7117 | 9452 | 16569 | 1815 | 996 | 2811 |
| 6 | Baroda | 7342 | 15640 | 22982 | 75.40 | 87.86 | 83.46 | 9068 | 17832 | 26900 | 849 | 426 | 1275 |
| 7 | Belgaum | 3369 | 15860 | 19229 | 84.98 | 96.93 | 94.60 | 5389 | 19512 | 24901 | 606 | 554 | 1160 |
| 8 | Dharwar | 5822 | 17386 | 23208 | 71.94 | 74.74 | 74.02 | 7948 | 22566 | 30514 | 1048 | 959 | 2007 |
| 9 | Amaravati | 3128 | 32654 | 35782 | 70.88 | 87.74 | 85.95 | 2393 | 8094 | 10487 | 389 | 1515 | 1904 |
| 10 | Wardha | 3657 | 24710 | 28367 | 73.75 | 84.32 | 82.78 | 5082 | 35258 | 40340 | 269 | 1006 | 1275 |
| 11 | Chandrapur | 3801 | 36222 | 40023 | 74.73 | 91.92 | 89.96 | 4837 | 41295 | 46132 | 754 | 2167 | 2921 |
| 12 | Bombay | 3510 | 19842 | 23352 | 50.01 | 75.56 | 70.17 | 3565 | 12516 | 16081 | 2879 | 3773 | 6652 |
| 13 | Ganjam | 8029 | 40404 | 48433 | 74.81 | 90.93 | 87.79 | 9700 | 47280 | 56980 | 1715 | 3737 | 5452 |
| 14 | Puri | 9870 | 30340 | 40210 | 66.82 | 79.94 | 76.26 | 12299 | 42897 | 55196 | 2625 | 3943 | 6568 |
| 15 | North Arcot | 10586 | 51135 | 61721 | 70.66 | 75.31 | 74.44 | 15253 | 111122 | 126375 | 2327 | 4836 | 7163 |
| 16 | Tanjavur | 4303 | 10709 | 15012 | 46.63 | 23.57 | 27.75 | 8627 | 51038 | 59665 | 1350 | 3187 | 4537 |
| 17 | Chengalpattu | 6938 | 57400 | 64338 | 69.14 | 83.03 | 81.27 | 9854 | 99749 | 109603 | 1547 | 4388 | 5935 |
| 18 | Purulia | 12745 | 35046 | 47791 | 68.45 | 86.24 | 81.79 | 16792 | 63408 | 80200 | 3499 | 3555 | 7054 |
| 19 | Varanasi | 11282 | 23907 | 35189 | 67.69 | 82.55 | 77.13 | 15552 | 29401 | 44953 | 1437 | 655 | 2092 |
| | TOTAL | 126400 | 520968 | 647368 | 69.39 | 79.50 | 77.29 | 179976 | 809051 | 989027 | 27659 | 41766 | 69425 |

# Appendix - 1 (d)

## SIDA Supported Districts and Operational Data MDT
## December 1993

| SR. NO. | DISTRICT | CHILD CASES AMONG NEW CASES | | GRADE II DEFORMITY CASES AMONG NEW | | SMEAR POSITIVE CASES AMONG NEW | |
|---|---|---|---|---|---|---|---|
| | | No. | % | No. | % | No. | % |
| 1 | Krishna | 10727 | 32.08 | 1117 | 3.44 | 1759 | 5.40 |
| 2 | Vizianagaram | 4859 | 16.20 | 1790 | 5.97 | 7526 | 25.10 |
| 3 | Srikakulam | 7413 | 30.31 | 705 | 2.88 | N.A. | N.A. |
| 4 | Vishakhapatnam | 8179 | 31.60 | 813 | 3.14 | 684 | 2.64 |
| 5 | Deoghar | 1480 | 12.60 | 1183 | 10.09 | N.A. | N.A. |
| 6 | Baroda | 2322 | 14.38 | 1131 | 7.00 | 1883 | 11.66 |
| 7 | Belgaum | 3675 | 23.53 | 533 | 3.41 | 1087 | 6.96 |
| 8 | Dharwar | 3373 | 16.87 | 770 | 3.85 | 842 | 4.21 |
| 9 | Amaravati | 10267 | 33.80 | 53 | 0.17 | 1916 | 6.32 |
| 10 | Wardha | 8647 | 26.59 | 98 | 0.60 | 3208 | 9.86 |
| 11 | Chandrapur | 8601 | 27.02 | 101 | 0.31 | 2131 | 6.69 |
| 12 | Bombay | 6623 | 33.64 | 1244 | 6.32 | 3806 | 19.33 |
| 13 | Ganjam | 14540 | 29.08 | 1975 | 3.95 | 1355 | 2.71 |
| 14 | Puri | 9323 | 30.52 | 301 | 0.98 | 474 | 1.55 |
| 15 | North Arcot | 21387 | 32.81 | 3115 | 4.77 | 2968 | 9.16 |
| 16 | Tanjavur | 12488 | 33.60 | 434 | 1.16 | 1969 | 5.29 |
| 17 | Chengalpattu | 25751 | 35.88 | 1445 | 2.01 | 1637 | 2.28 |
| 18 | Purulia | 10685 | 17.88 | 3147 | 5.26 | 1587 | 2.65 |
| 19 | Varanasi | 5599 | 17.47 | 1537 | 4.79 | 3282 | 10.23 |
| | TOTAL | 175939 | 26.62 | 21492 | 3.38 | 38114 | 6.34 |

# Appendix - 2 (a)

## Epidemiological Data
## December 1993

| SR. NO. | DISTRICT | REGISTERED PREVALENCE RATE PER 1000 | | | | NEW CASE DETECTION RATE PER 1000 | | | MB RATE (%) AMONG NEW CASES | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Before MDT | | Current | % Change | Before MDT | Current | % Change | Before MDT | Current | % Change |
| | | Estimated | Regd. | | | | | | | | |
| 1 | Krishna | 11.30 | 9.10 | 1.08 | 88.13 | 2.45 | 0.67 | 72.65 | 19.67 | 13.70 | 30.35 |
| 2 | Vizianagaram | 16.00 | 13.20 | 1.19 | 90.98 | 1.49 | 0.68 | 54.36 | 26.42 | 20.21 | 23.50 |
| 3 | Srikakulam | 16.20 | 15.70 | 0.95 | 93.95 | 1.31 | 0.48 | 63.36 | 15.75 | 18.51 | 17.52 |
| 4 | Vishakhapatanam | 9.30 | 9.37 | 0.58 | 93.81 | 1.09 | 0.67 | 38.53 | 24.87 | 13.45 | 45.92 |
| 5 | Deogarh | 20.00 | 10.88 | 3.06 | 71.87 | 5.38 | 1.89 | 64.87 | 37.67 | 45.17 | 19.90 |
| 6 | Baroda | 7.80 | 4.31 | 0.39 | 90.95 | 0.86 | 0.41 | 52.33 | 32.53 | 30.86 | 5.13 |
| 7 | Belgaum | 6.00 | 3.47 | 0.32 | 90.78 | 0.63 | 0.33 | 47.62 | 23.01 | 21.16 | 8.04 |
| 8 | Dharwar | 4.80 | 4.40 | 0.57 | 87.04 | 0.98 | 0.49 | 50.00 | 5.49 | 24.52 | 346.60 |
| 9 | Amaravati | 6.85 | 5.00 | 0.95 | 81.00 | 2.11 | 1.51 | 28.44 | 7.04 | 5.18 | 26.42 |
| 10 | Wardha | 10.09 | 9.68 | 1.19 | 87.71 | 2.96 | 1.81 | 38.85 | 12.86 | 6.00 | 53.34 |
| 11 | Chandrapur | 12.23 | 12.14 | 1.65 | 86.41 | 2.99 | 2.64 | 11.70 | 9.76 | 7.73 | 20.79 |
| 12 | Bombay | 3.50 | 1.86 | 0.67 | 63.98 | 0.70 | 0.70 | 0.00 | 17.85 | 17.85 | 0.00 |
| 13 | Ganjam | 15.57 | 13.57 | 1.73 | 87.25 | 1.80 | 1.75 | 2.78 | 19.81 | 15.91 | 19.68 |
| 14 | Puri | 12.80 | 10.50 | 1.83 | 82.57 | 1.13 | 1.43 | 26.54 | 27.98 | 19.06 | 31.88 |
| 15 | North Arcot | 18.35 | 15.25 | 1.52 | 90.03 | 1.09 | 0.71 | 34.86 | 28.02 | 12.68 | 54.70 |
| 16 | Tanjavur | 16.00 | 6.50 | 1.00 | 84.61 | 0.56 | 0.85 | 51.78 | 13.56 | 8.90 | 34.36 |
| 17 | Chengalpattu | 13.60 | 12.10 | 1.28 | 89.42 | 2.18 | 0.81 | 62.84 | 7.81 | 8.44 | 8.07 |
| 18 | Purulia | 14.69 | 14.69 | 3.06 | 79.17 | 2.12 | 1.16 | 45.28 | 41.23 | 30.27 | 26.58 |
| 19 | Varanasi | 10.00 | 6.40 | 0.44 | 93.12 | 2.66 | 0.26 | 90.23 | 50.32 | 32.30 | 35.81 |

# Appendix - 2 (b)

Epidemiological Data
December 1993

| SR. NO. | DISTRICT | DEFORMITY RATE ( Gr. 2 ) AMONG NEW CASES | | | CHILD RATE AMONG NEW CASES | | |
|---|---|---|---|---|---|---|---|
| | | Before MDT | Current | % Change | Before MDT | Current | % Change |
| 1 | Krishna | 3.52 | 3.19 | 9.38 | 22.62 | 32.43 | 43.37 |
| 2 | Vizianagaram | 7.43 | 2.42 | 67.43 | 74.40 | 18.75 | 74.80 |
| 3 | Srikakulam | 4.85 | 1.88 | 61.24 | 28.63 | 26.68 | 6.81 |
| 4 | Vishakhapatanam | 7.22 | 2.89 | 59.97 | 23.97 | 28.53 | 19.02 |
| 5 | Deogarh | 19.59 | 2.58 | 86.83 | 11.58 | 14.77 | 27.55 |
| 6 | Baroda | 8.61 | 4.91 | 42.97 | 9.48 | 18.71 | 97.36 |
| 7 | Belgaum | 4.28 | 3.13 | 26.87 | 18.46 | 26.24 | 42.14 |
| 8 | Dharwar | 3.21 | 2.95 | 8.09 | 12.07 | 20.63 | 70.92 |
| 9 | Amaravati | 2.59 | 0.39 | 84.94 | 9.73 | 25.74 | 164.50 |
| 10 | Wardha | 0.63 | 0.00 | 100.00 | 22.01 | 26.66 | 21.13 |
| 11 | Chandrapur | 0.81 | 0.71 | 12.35 | 9.34 | 27.03 | 189.40 |
| 12 | Bombay | 5.35 | 5.35 | 0.00 | 37.61 | 37.61 | 0.00 |
| 13 | Ganjam | 16.18 | 1.63 | 89.93 | 20.29 | 36.24 | 78.61 |
| 14 | Puri | 0.54 | 0.79 | 46.30 | 5.12 | 30.99 | 505.27 |
| 15 | North Arcot | 6.71 | 1.97 | 70.64 | 30.44 | 43.36 | 42.44 |
| 16 | Tanjavur | 8.56 | 2.31 | 73.01 | 49.36 | 42.78 | 13.33 |
| 17 | Chengalpattu | 3.19 | 1.12 | 64.89 | 5.08 | 47.59 | 836.81 |
| 18 | Purulia | 3.29 | 1.74 | 47.11 | 17.90 | 21.04 | 17.54 |
| 19 | Varanasi | 13.29 | 11.18 | 15.88 | 8.92 | 13.71 | 53.69 |

# Appendix - 3

Performance Related to Duration of MDT Program

| SR. NO. | INDICATOR | DURATION OF MDT PROGRAM | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | <= 5 YEARS (2 DISTRICTS) | | | 6-8 YEARS (8 DISTRICTS) | | | >= 9 YEARS (9 DISTRICTS) | | |
| | | Before | Current | % Change | Before | Current | % Change | Before | Current | % Change |
| 1 | Registered Prevalence Rate /1000 | 7.04 | 0.77 | -89.06 | 7.62 | 0.92 | -87.93 | 11.97 | 1.43 | -88.05 |
| 2 | New Case Detection Rate /1000 | 0.77 | 0.74 | -3.90 | 2.18 | 0.77 | -64.68 | 1.76 | 0.94 | -46.59 |
| 3 | MB Proportion % | 16.71 | 14.67 | -12.21 | 24.23 | 15.1 | -37.68 | 25.09 | 17.57 | -29.97 |
| 4 | Child Proportion % | 40.70 | 39.45 | -3.07 | 11.47 | 30.8 | 168.53 | 20.16 | 27.82 | 38.00 |
| 5 | Deformity Proportion % | 6.21 | 4.27 | -31.24 | 3.75 | 2.18 | -41.87 | 10.55 | 1.75 | -83.41 |

# Appendix - 4

Selected Districts: New Case Detection Rate

| SR. NO. | DISTRICT | TOTAL NEW CASES | MB CASES | PB CASES | MONO LESION CASES | TOTAL NCDR / 1000 | MB NCDR / 1000 | PB NCDR / 1000 | MONO NCDR / 1000 |
|---|---|---|---|---|---|---|---|---|---|
| 1 | Baroda | 1325 | 409 | 916 | 114 | 0.41 | 0.13 | 0.28 | 0.04 |
| 2 | Belgaum | 1181 | 250 | 931 | 467 | 0.33 | 0.07 | 0.25 | 0.13 |
| 3 | Dharwar | 1725 | 423 | 1308 | 808 | 0.49 | 0.12 | 0.37 | 0.23 |
| 4 | Amaravati | 3046 | 158 | 2888 | 981 | 1.52 | 0.08 | 1.44 | 0.59 |
| 5 | Ganjam | 5518 | 878 | 4640 | 2717 | 1.75 | 0.28 | 1.46 | 0.86 |
| 6 | Puri | 5146 | 981 | 4165 | 1779 | 1.43 | 0.27 | 1.16 | 1.16 |
| 7 | Varanasi | 1269 | 410 | 859 | 90 | 0.26 | 0.09 | 0.18 | 0.02 |
| | TOTAL | 19210 | 3509 | 15701 | 6956 | 0.81 | 0.15 | 0.66 | 0.29 |

# Appendix - 5

## Proportion of MB Positive Cases

| SR. NO. | DISTRICT | BEFORE MDT | CURRENT | % CHANGE |
|---|---|---|---|---|
| 1 | Krishna | 3.90 | 2.95 | -24.36 |
| 2 | Baroda | 13.89 | 12.30 | -11.45 |
| 3 | Belgaum | 11.96 | 6.50 | -45.65 |
| 4 | Dharwar | 2.10 | 5.60 | 166.67 |
| 5 | Ganjam | 7.05 | 0.52 | -92.62 |
| 6 | Puri | 2.80 | 0.29 | -89.64 |
| 7 | North Arcot | 9.60 | 2.14 | -77.71 |
| 8 | Chengalpattu | 3.88 | 1.77 | -54.38 |
| 9 | Varanasi | 11.78 | 0.55 | -95.33 |
|  | TOTAL | 3.13 | 2.34 | -67.18 |

# Appendix - 6

## Cumulative Incidence of Reactions

| SR. NO. | DISTRICT | TOTAL CASES OF MDT | NO. OF PATIENTS WITH TYPE I & II REACTION | % |
|---|---|---|---|---|
| 1 | Baroda | 27537 | 382 | 1.39 |
| 2 | Dharwar | 31352 | 529 | 1.69 |
| 3 | Wardha | 34266 | 238 | 0.69 |
| 4 | Chandrapur | 44491 | 152 | 0.34 |
| 5 | Chengalpeth | 79161 | 58 | 0.07 |
| 6 | Varanasi | 45624 | 1601 | 3.51 |
|  | TOTAL | 262431 | 2960 | 1.13 |

# Appendix - 7

## Voluntary Reporting

| SR. NO. | DISTRICT | TOTAL NEW CASES DETECTED | VOLUNTARY CASES | % |
|---|---|---|---|---|
| 1 | Krishna | 32422 | 12708 | 39.20 |
| 2 | Srikakulam | 24453 | 12982 | 53.09 |
| 3 | Vishakhapatanam | 25877 | 9567 | 36.97 |
| 4 | Deogarh | 11718 | 7994 | 68.22 |
| 5 | Baroda | 16150 | 9696 | 60.04 |
| 6 | Belgaum | 15614 | 3847 | 24.64 |
| 7 | Dharwar | 19996 | 9001 | 45.01 |
| 8 | Amaravati | 30317 | 9482 | 31.28 |
| 9 | Wardha | 32517 | 12926 | 39.75 |
| 10 | Chandrapur | 31832 | 13358 | 41.96 |
| 11 | Tanjavur | 37162 | 8323 | 22.40 |
| 12 | Chengalpattu | 71770 | 16318 | 22.74 |
| 13 | Purulia | 59752 | 17071 | 28.57 |
| 14 | Varanasi | 32061 | 11636 | 36.29 |
|  | TOTAL | 441641 | 154909 | 35.08 |

# Appendix - 8

## Leprosy Profile in Female Cases

| SR. NO. | DISTRICT | TOTAL NEW CASES | FEMALE CASES AMONG NEW CASES | % OF FEMALE CASES |
|---|---|---|---|---|
| 1 | Vishakhapatanam | 25877 | 10861 | 41.97 |
| 2 | Baroda | 16150 | 7056 | 43.69 |
| 3 | Wardha | 32517 | 9532 | 29.31 |
|  | TOTAL | 74544 | 27449 | 36.82 |

# Appendix - 9

## Deformity Data: Selected Districts

| SR. NO. | DISTRICT | DEFORMITY (GRADE 2) CASES IN OLD AND NEW LEPROSY CASES | | | | |
|---|---|---|---|---|---|---|
| | | OLD CASES | CUMULATIVE NEW CASES | NCDR OF DEFORMITY /1000 | TOTAL (OLD + NEW ) | P.R. OF DEFORMITY |
| 1 | Krishna | 1499 | 1117 | 0.30 | 2616 | 0.71 |
| 2 | Srikakulam | 477 | 705 | 0.30 | 1182 | 0.51 |
| 3 | Vishakhapatanam | 242 | 813 | 0.25 | 1055 | 0.32 |
| 4 | Deogarh | 1838 | 1183 | 1.28 | 3021 | 3.29 |
| 5 | Baroda | 1156 | 1131 | 0.35 | 2287 | 0.72 |
| 6 | Belgaum | 1187 | 533 | 0.15 | 1720 | 0.48 |
| 7 | Dharwar | 982 | 770 | 0.22 | 1752 | 0.50 |
| 8 | Amaravati | 25 | 53 | 0.03 | 78 | 0.04 |
| 9 | Wardha | 1075 | 98 | 0.18 | 1173 | 1.19 |
| 10 | Chandrapur | 219 | 101 | 0.06 | 320 | 0.18 |
| 11 | Tanjavur | 5268 | 434 | 0.00 | 5702 | 1.26 |
| 12 | Chengalpattu | 4570 | 1445 | 0.31 | 6015 | 1.30 |
| 13 | Purulia | 624 | 3147 | 1.42 | 3771 | 1.70 |
| 14 | Varanasi | 1504 | 1537 | 0.32 | 3041 | 0.63 |
| | TOTAL | 20666 | 13167 | 0.32 | 33833 | 0.82 |

# Appendix - 10

## Relapses

| SR. NO. | DISTRICT | MDT RELAPSE TOTAL | MONO RELAPSE TOTAL |
|---|---|---|---|
| 1 | Krishna | 142 | 148 |
| 2 | Srikakulam | 168 | 354 |
| 3 | Vishakhapatanam | 163 | 158 |
| 4 | Baroda | 66 | 110 |
| 5 | Belgaum | 116 | 14 |
| 6 | Wardha | 10 | 65 |
| 7 | Tanjavur | 103 | 64 |
| 8 | Chengalpattu | 438 | 551 |
| 9 | Purulia | 406 | 106 |
| 10 | Varanasi | 1334 | 0 |
| | TOTAL | 2946 | 1570 |

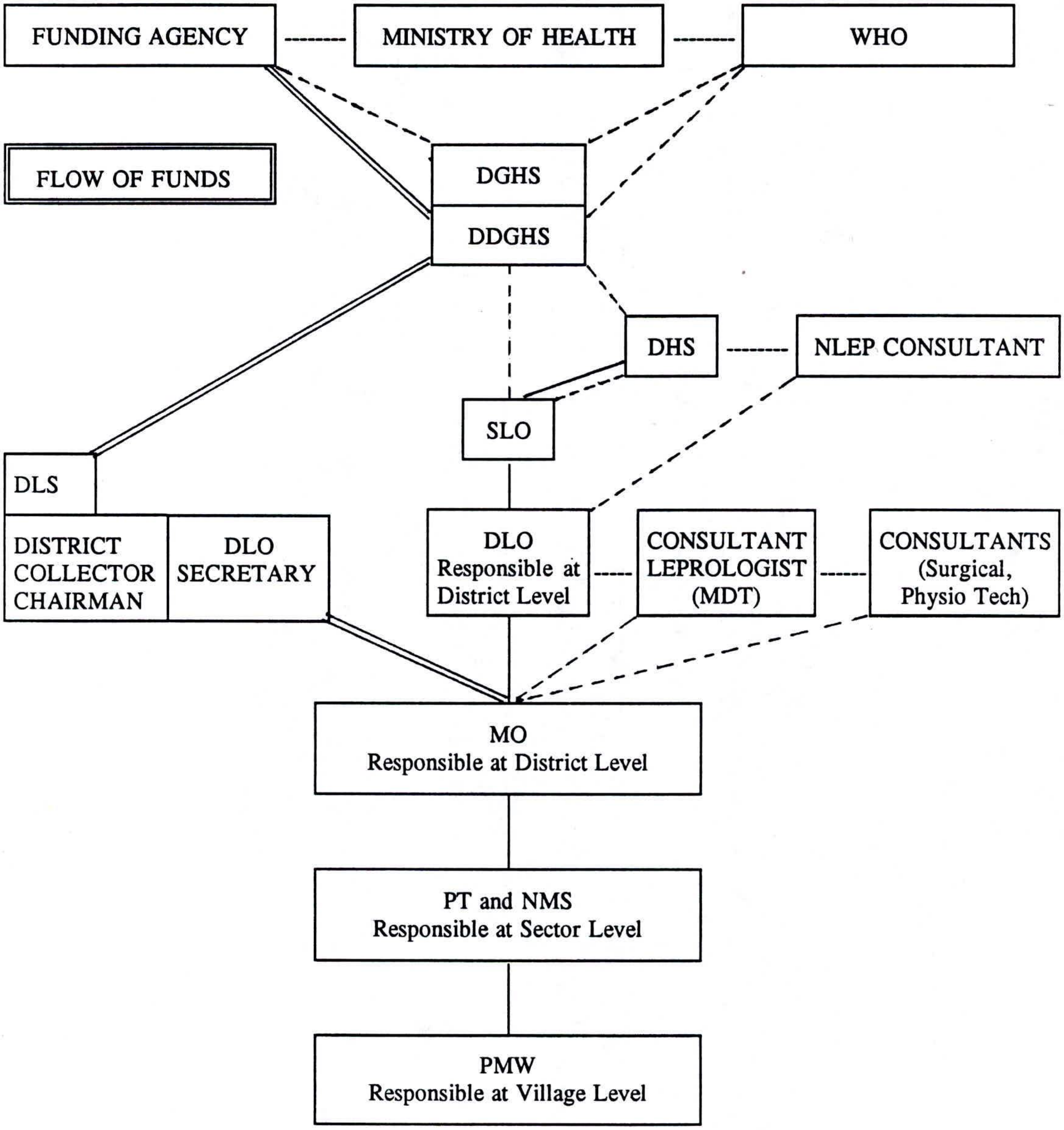
# Appendix - 11

Screening in SIDA MDT Districts

| SR. NO. | DISTRICT | TOTAL NO. OF REGISTERED CASES ON RECORD BEFORE SCREENING | | | ACTIVE CASES AFTER SCREENING | | | DELETION DURING SCREENING | | | % OF DELETIONS |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | MB | PB | Total | MB | PB | Total | MB | PB | Total | |
| 1 | Krishna | 6576 | 21460 | 28036 | 6541 | 15404 | 21945 | 35 | 6056 | 6091 | 21.73 |
| 2 | Deogarh | 2634 | 8433 | 11067 | 2483 | 5179 | 7662 | 151 | 3254 | 3405 | 30.77 |
| 3 | Dharwar | 3916 | 9347 | 13263 | 3819 | 9221 | 13040 | 97 | 126 | 223 | 1.68 |
| 4 | Amaravati | 2393 | 8094 | 10487 | 1988 | 7316 | 9304 | 405 | 778 | 1183 | 11.28 |
| 5 | Chandrapur | 2642 | 17095 | 19737 | 2496 | 14725 | 17221 | 146 | 2370 | 2516 | 12.75 |
| 6 | Varanasi | 3645 | 13380 | 17025 | 3645 | 11338 | 14983 | 0 | 2042 | 2042 | 11.99 |
| | TOTAL | 21806 | 77809 | 99615 | 20972 | 63183 | 84155 | 834 | 14626 | 15460 | 15.52 |

# APPENDIX - 12

## ORGANIZATION SHOWING LINE OF COMMAND AND FLOW OF FUNDS

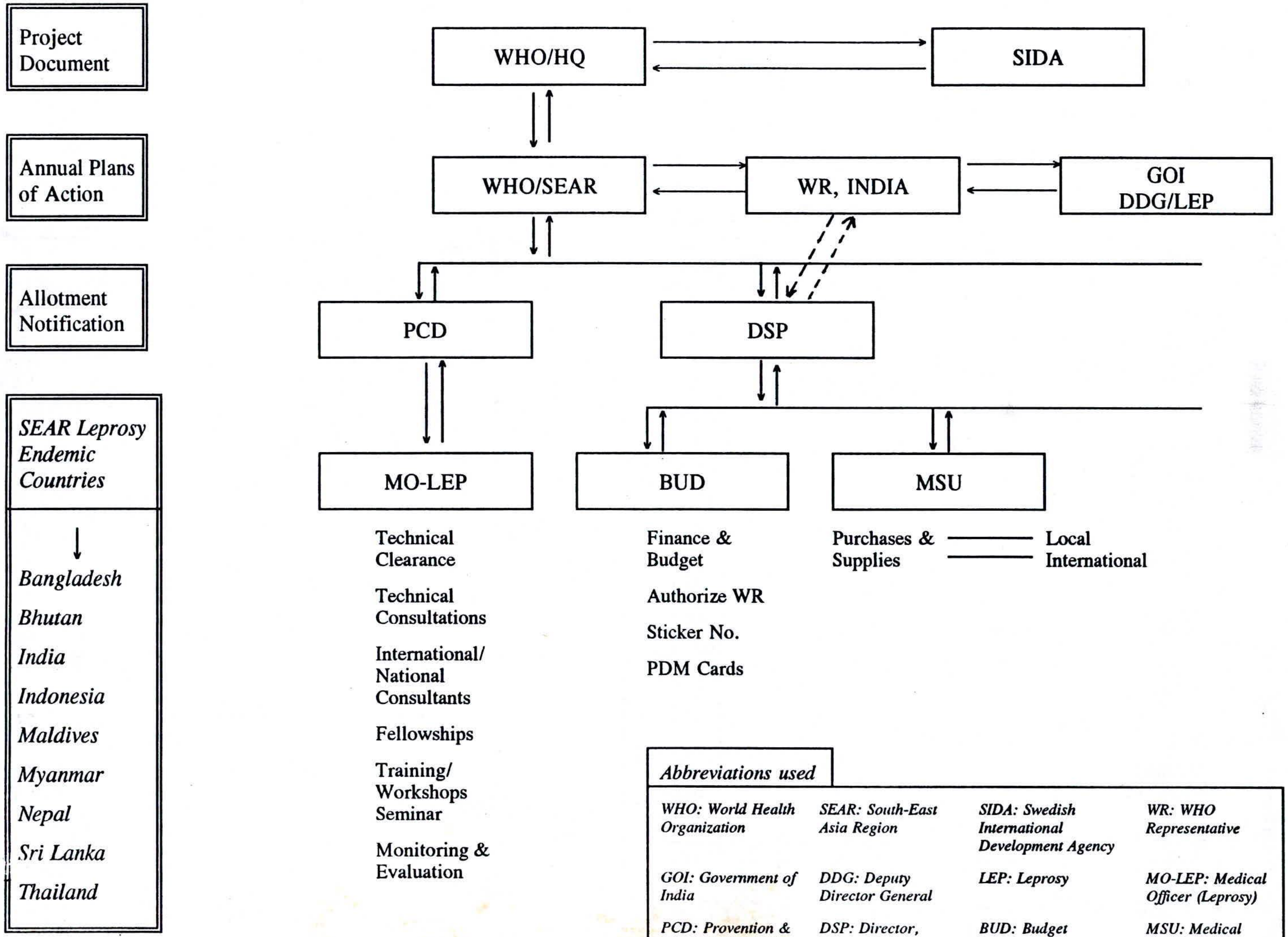


**INDEX**

——— CONTROL

------ CO-ORDINATOR

═══ FLOW OF FUNDS



*Abbreviations used*

*WHO: World Health Organization*
*SEAR: South-East Asia Region*
*SIDA: Swedish International Development Agency*
*WR: WHO Representative*
*GOI: Government of India*
*DDG: Deputy Director General*
*LEP: Leprosy*
*MO-LEP: Medical Officer (Leprosy)*
*PCD: Provention & Control of Diseases*
*DSP: Director, Support Programme*
*BUD: Budget*
*MSU: Medical Supply Unit*

# L. BROLIN

## 1. THE ORGANIZATIONAL SET-UP

**LB's Comments:** This is a summary of my notes and I suppose that Malcolm has a lot more to add. My observations and conclusions are but one input in the discussion within the team, and might very well be questioned if other team members have made other observations.

### The Pros and Cons of a Vertical Program

The NLEP has been carried out as a strictly vertical program with a special cadre of staff. There seems to be a mutual understanding among the Ministry of Health and Family Welfare, WHO, UNICEF, and representatives of the NGO-sector that the verticality of the program has been necessary up till now.

The informants consider that the program would have been much less efficient if it had been integrated in the primary health care system. The main reasons being that leprosy and care of leprosy patients is considered issues of lowest priority within the Ministry of Health and Welfare. Consequently, the Ministry would not have provided enough resources to attain the goal of eradication of leprosy if earmarking had not existed. "The majority of the resources would have been used for family planning" was a common opinion among the informants.

The informants further stressed the difficulty to find health care personnel who would like to work with leprosy if they did not receive incentives as this kind of work has a very low status in the Indian society.

Another consideration was that the primary health care system as such is of a very rudimentary quality. Some informants expressed this situation drastically; "There has been no primary health care to be integrated into". Such views are common. In a Conference held in 1991, Professor Deodhar from Pune stated for example that the rapid expansion of the health services infrastructure has implied considerable loss of quality, capability and effectiveness.This has in turn resulted in a lost credibility and poor use of health services. (Document from IAL National Workshop at Karigiri, 1991, p 8-9). Similar views were expressed by SIDA staff in India.

One negative consequence of having a vertical program has often been mentioned; the stigma of leprosy and of the leprosy patients increases. Patients do simply not want to be identified as leprosy cases but as any ill person. Many have experienced that when neighbours and relatives observe that somebody visits the special leprosy clinic, or is visited by a special leprosy worker, then the person is provided a long-lasting stigma.

There is a general worry about the future development of the vertical program, and this worry often refers to the situation of the staff. The staff and the equipment was at the beginning supposed to be transferred from one district to another with the eradication of leprosy cases, as only the high-endemic areas in fact needed a strictly vertical set-up. However, these plans did not function in reality, the staff did not want to move. Instead more staff was employed. As a consequence of this development there is now a considerable large number of persons who need to be retrained. Another problem to be solved is the issue about incentives. The staff claims a continuation of the same conditions.

## The Role of WHO

The major role of WHO within the NLEP program is to provide technical advice.

This has implied focus on detecting cases, providing drugs and giving medical treatment. Surveys of households and examination of families in endemic areas have implied that a large percentage of all leprosy cases have been detected. Using MDT as main strategy for control of leprosy has turned out to be very efficient, and in this respect the technical guidance of WHO has been of utmost importance. At the same time both the verticality and the medicalization of the program have been reinforced by the presence of WHO, as such a view is also predominant within the Ministry. Had an organization with a different approach been involved in the implementation the program would have developed differently. The Danlep commitment is but one such example.

SIDA chose WHO as channel for its financial support already from the beginning in 1979. WHO was developing drugs for better treatment of leprosy, and the organization had experiences of special research and training. The main reason for SIDA's choice was however WHO's special privileges regarding importation of drugs and equipment. (From G. Kronvall. Letter to SIDA, January 7, 1984)
The general opinion among the informants is that WHO's role as financial channel could have been carried out through any private company or public organization. The strength of WHO is not on the administrative level but based on a highly professional, medical, manner to implement programs.

WHO has also played a pertinent role in designing and carrying out four independent evaluations of the program. Furthermore, WHO-consultants have been involved in the training and supervision of certain staff categories and has supported the 40 leprosy consultants, financed by SIDA, with training and supervision. These consultant are even most often (wrongly) called WHO-consultants.

SIDA has however criticized WHO for not following up the SIDA support and for lack of reporting. The Ministry has been the subject of the same criticism, although it has turned out that agreements often have been vaguely formulated. The criticism was particularly strong in the mid-1980s.

## SIDA'S Role

SIDA's role has been that of financier, while WHO has played the role of the implementor. The support has mainly been used for purchase of drugs, which originally was not the aim. SIDA has tried to change this a number of times but obviously not succeeded.

SIDA has also continuously suggested financing a project-coordinator. The aim of such a post was officially to improve the information flow and the monitoring. There is a lot that also points towards SIDA wanting more influence and control of the support. As the Indian regulations do not allow foreigners in the Ministries SIDA came up with different alternatives throughout the co-operation. However, no solution has been considered satisfactory.

SIDA has questioned the verticality of the program during the years of support and has suggested a broadening of the contents, suggestions that have not been taken into consideration. This, in turn, may be explained by the fact that SIDA is known as a very flexible donor and that statements made by SIDA or SIDA consultants are perceived as unconditioned suggestions.

If SIDA had wanted to influence the design of the program more it would have been more fruitful to use other models, for example the Danlep approach, which could be defined as a bilateral project. Danlep is actively involved in the program but has considered it necessary also to work with other actors outside the very program.

Such an approach would also have been more cost-efficient, as the administrative costs are estimated at approximately 8%. WHO has claimed 13% of the total sum of the SIDA-support for overhead costs, a sum that has often been criticized to be too high and was one reason why SIDA searched for alternative channels in mid- 1980s.

It is also worthwhile raising the question if the SIDA support had been more efficient had it been channelled directly to the states or the districts.

## 2. SOCIAL IMPACT OF THE PROGRAM

**LB's Comments:** The following pages are supposed to take up the question about social impact in the TOR, page 2. Some questions that I have in mind are:

* Has knowledge about leprosy been changed?
* Have attitudes towards leprosy changed and the fear of leprosy vanished?
* Do people behave differently towards leprosy now?
* Have patients been involved in the design of the program
* Has the socio-economic situation for (ex-) patients changed?

My disposition of the text is approximately like this:

a. to define the problem
b. describe measures within the government program
c. actual results/changes of the program
d. SIDA's policy and commitment to the issue

As these conclusions are only based on some interviews and documents I would be happy if they can be corrected and completed by the rest of the team. Has Jean for example got any impression about measures to improve the socio-economic situation of the patients?

* * * * * * * * * * * * * *

### Little Involvement from Social Scientists

That leprosy is not only a medical problem but has also many social dimensions is undisputed. As long as medical technology had little to offer leprosy was mainly a social problem with little involvement from the medical community. The problems of existing patients were tackled by non-medical sectors.

When the dapsone therapy started and later was followed by multidrug therapy the picture changed, and leprosy became an issue for medical experts. The major problem became how to detect and how to treat leprosy patients. However, even if the combination of drugs was the focus of the program it has not been possible to exclude social problems completely. Such problems often have far more serious consequences than the medical problems as the perception and fear of leprosy is deeply rooted in the society.

In order to bring social scientists into the field a centre for social science research on leprosy was created in Wardha in 1985. Social scientists were invited to seminars in order to encourage a cooperation between them and leprologists.

Despite these efforts there are very few traces of sociological or anthropological influence in the government program, a natural consequence of the vertical, narrow and efficient set-up of the program. (R. K. Mutatkar, in Document from The National Workshop, March 1991, p 14-15). The lack of involvement of social scientists is obvious in almost all program documents, guidelines and publications about facts and figures.

The social dimension of leprosy has rather become a rest category to different medical aspects. Different types of social issues are packed together and there seems to be little correspondence between policy and practice. The definition of health education is such a case.

Health Education in Policy and Practice

The official aims with health education are:

* to create awareness on the availability of free treatment
* to develop knowledge on the nature of leprosy, its amenability to cure, recognition of early signs of the disease and prevention of deformities
* to promote social integration of the leprosy patients and
* to promote community commitment to the program

In order to fulfil the listed objectives an elaborated strategy is needed. Even if it is proclaimed that health education is central to the program, in practice it continues to be a peripheral activity consisting of films, pamphlets, and posters. (See for example Plan of operation for SIDA/WHO assistance, April-December 1991 and Health Education Activities during 1992-93).

With the exception of set of posters or pamphlets, there is little assistance from the central level to states and districts. (According to the document from 1993 mentioned above 25% of the provided amount is used for films, slide projector etc, 25% for creating public awareness, 25% on posters, banners, and photographs and 25% for other activities). How activities are carried out and what impact they have is very much related to local initiatives and NGOs, and there is probably a considerable variation between states and districts.

According to most of the informants the impact of the health education implemented by the government machinery is negligible. The impact of campaigns like "leprosy is curable" is for example uncertain. In 1986 71% of the persons interviewed and in 1991 72% believed that leprosy is curable. However, the perception of the spread of the disease may have changed. In 1986, 52% thought that leprosy does not spread easily. In 1991 this figure had increased to 59%. (From The Independent Evaluations) 1991).

Tackling such a problem as stigma is still more difficult as this means changing traditional values. To what extent such changes have occurred is also difficult to know, and the independent evaluations do hardly give any reliable answers. The percentage of leprosy patients living together with their families was just as high in 1991 as in the mid-eighties, i e more than 90%. A question about the inheritance introduced in the latest evaluation showed that 57% thought that the disease is not inherited, while 20% thought it was.

Different studies have shown that many persons have a strong fear and suspicion about the disease and believe that the disease is caused by sexual promiscuity, by visiting ancestors banned by their sins or by something else that is inexplicable.

Yet, there is a belief within the program that only "true facts" are presented, stigma will softly and suddenly vanish, and give way for rational attitudes and behaviours. (See for example Duggal et al, 1988, page 10). One precondition for such a development is however that the community is involved, and that patients are listened to. This is not the case for the moment.

There are many testimonies of patients who find themselves devalued, discriminated, insulted, and excluded by the society through stigmatization. And there are many with severe constraints in schooling, employment, marriage, and old age. However, these experiences have not been utilized in the design of the government program.

This reflects the one-way relation within the program and the lack of involvement of the patients themselves. It also reflects the lack of involvement of social scientists, educators and social workers in the design and implementation of the program and is a sharp contrast to projects implemented by NGOs and Danlep.

### Participatory Methods - Left to NGOs

The program has been designed as a vertical and thereby narrow program. Such a design does not embrace community participation or social actions. The philosophy of the program is that by delivering adequate drugs leprosy - and thereby also prejudices towards the disease - will be eradicated.

The training of the government program staff is based on the perception that both patients and community are receivers of service. This has often been criticized. Dr Raja, Madurai Institute of Social Work has for example argued that schools of social work have to include intercommunication methods.

In the strategies used by NGOs and other organizations social action and community participation are inherent parts. Danlep is an example of an agency that has chosen to work together with both program staff and groups outside the program; teachers' organizations, women's organizations, youth organizations, and local religious bodies. Traditional health workers like dais and anganwadi workers function as voluntary barefoot doctors. Furthermore, Danlep makes efforts to involve staff from the primary health care institutions.

Different types of communication methods and actions are used by Danlep, Unicef and NGOs, depending on local traditions.

"The point is not that a single message is being communicated to a given receiver, rather it is that a much wider communication is taking place, with multiple media, a continuing and dynamic exchange of ideas, experiences, views, of sharing and a constant feedback, all of which energize and enrich the anti-leprosy program, making it unique". (U. Butulia. No stone unturned, Danlep, 1992.)

## SIDA Urged Better Health Education

Since the beginning of the SIDA support the organization has expressed great results from the health education in the program. The aim was formulated as "creating individual and community awareness of leprosy". (From Preparation document for the agreement during 1984/85-1988/89)

SIDA did not entered upon how such a health education was to be carried out by government staff, but has continuously stated that the health education was a weak part of the program.

One of the reasons for considering to replace WHO with Unicef in the mid-eighties was that SIDA was unsatisfied with the manner WHO handled health education. The negotiations ended by a Unicef commitment in three of the districts, and that SIDA financed a study about knowledge, attitudes and behaviours related to leprosy.

If it also resulted in more or better health education and community participation in the three districts has not been possible to verify. In Unicef's budget about 1.5% was allocated to health education.
It is however obvious that SIDA could not influence the general policy for health education in the program.

In the project document produced for the agreement 1990/91-1992/93 SIDA was asked to provide special funds to use folk-media as the health education earlier largely had aimed at urban and literate population.

## No Stress on Community Participation from SIDA

In the late 1970s the Indian leprosy program was presented to SIDA as different from programs in other countries - it was a community oriented project. However, "community oriented" simply meant that the data was collected in a way that epidemiological analyses would be possible - not that the program aimed at community participation.

"The effect of the intensive treatment is studied not only in the individual patient but also using epidemiological parameters in order to measure the degree of elimination of the infectious loads in the community" (Kronvall, Memo December 1979).

In the original project document the main aims were expressed as

a) using different drugs under controlled conditions,

b) providing the national leprosy program with a special adhesive tape, and c) financing locally available equipment. Special teams were suggested for monitoring and evaluating the results. Health education should be given during surveys and the intensive treatment period "for detection and regular treatment of bacteriologically positive cases".

Consequently, it was made quite clear that community orientation or community participation was no integral part of the program. SIDA suggested that the program be more community oriented, but no changes were made. SIDA obviously accepted this, and with the exception of the period 1984-1985 community participation has not been an issue SIDA has stressed.

## 3. THE GENDER PERSPECTIVE

**LB'S Comments:** This is my contribution to question 5 in our model. I think that this part could come in under the epidemiological description of the medical impact of the program. Which categories have been reached and which have not? Is there a gender difference? (beside geographical, age...) If so, how could this be explained and what changes are necessary within the program?

### Why More Men Than Women?

The majority of persons reporting to the program are men. WHO researchers suggest that this is simply because the risk of developing leprosy is lower for women than for men. This is however an explanation to be questioned. Conventionally, all para-medical leprosy workers have been men. Considering existing norms and values in many of the Indian states this must be seen as a severe constraint for reaching women. Social norms do not allow women to expose their bodies to men. Moreover, women are brought up to ignore illnesses.

It can also be argued that even if the risks for leprosy are less for women than men the disease should not only be the concern of men, and women have the same right to knowledge about the disease.

Secondly, many women who suffer from leprosy have made cruel experiences being thrown out of their homes when the husbands have detected the disease. Thirdly, the possibility of early detection in a child is increased if women are involved. Fourthly, much of the community life is carried on through the women.

In some Danlep-districts a number of efforts have been made to involve both women and men, girls and boys. Women and girls have been trained to detect leprosy. In some places it has turned out that women do not want to be singled out, in other places religious groups or women groups have been active.

The leprosy workers in the Danlep districts, although very much part of the system, have adopted a different and carefully considered approach; that of informing, involving and empowering the entire community. A first step for them has been to become part of the community, gradually blurring the distinction between the patient and the doctor, the healer and the healed.

Where there is a lack of confidence, especially among the women, the leprosy workers reach them through the existing community structures such as the Mahila Mandals, religious groups or through more formal structures such as the Anganwadis, PHCs, vocational training centres or institutions of learning. ( From A. Butalia. The story within the story, p 12, Danlep, 1992).

## SIDA'S Commitment

A general goal of all SIDA support is that it should enhance and empower both women and men. In order to know to what extent this requirement is fulfilled SIDA generally recommends gender aggregated statistics. This has also been the case with NLEP.

In the project document prepared for the last agreement (1990/91-1992/93) GOI promised to modify the information system to obtain gender-wise statistics. However, according to the design of annual and monthly reporting presented in the guidelines 1992 no gender-wise statistics is required. So far, such statistics has only been presented for five districts. In the last agreement it was also stated that a cooperation with women's organizations was to take place, but the team could not get any information about the progress.

SIDA has further earmarked resources for a seminar on women and leprosy. Such a seminar has not yet been carried out.

Since 1984 SIDA has kept recommending that the program includes female health workers in the leprosy team. The aim has been to increase the rate of detection of female leprosy cases at an early stage of the disease. Swedish consultants were well aware that many problems had to be solved in relation to female workers, but insisted in such a change. (In some districts a single woman living in a remote area without family relations will for example easily loose prestige and status. Life could be very difficult for her).

In the last agreement GOI assured that efforts were to be made, but yet there are still very few female paramedical workers in the government program. The main reasons given from the management of the program are hardly credible. The development rather shows that neither WHO nor the Ministry consider lack of female paramedical workers as any serious constraint for the program. Consequently, they do not consider it worth while to make any strong efforts to change the situation.

In summary, SIDA's recommendations have not been followed-up by WHO or the government. The activities have so far been gender-blind. The Danlep experiences show however that other approaches both are possible and fruitful.

## PERSON'S MET

### Ministry of Health and Family Welfare

Dr. Mittal, Director General, NLEP

### WHO

Dr N K Shah, WHO representative to India, New Delhi
Dr P W Samdup, Medical Officer/Lepra, New Delhi
Dr M J George, National Program Officer, New Delhi
Dr Pattanyak, Acting Director, PCD, Searo, New Delhi
Mr A K Mitra, Budget Officer, Searo, New Delhi

### UNICEF

Mrs. Geeta Athreya, Project Officer, Health Communications, N. Delhi
Dr. Tewabech Bishaw, Project Officer Health, New Delhi
Dr. L.N. Balaji, Project Officer Community Health, New Delhi
Mrs. Ann-Lis Svensson, Project Officer, New Delhi

### SIDA

Mrs. Inese Zalitis, former health program officer in New Delhi
Mrs. Gudrun Hubendick, former health program officer, Stockholm
Mrs. Ingrid Cornell, present health program officer, Stockholm
Mrs. Gunilla Essner, present health program officer, New Delhi
Mr. Jan-Olov Agrell, Head of DCO, New Delhi
Mrs. Rita Sarin, Advisor, Women's program, New Delhi

### SIDA Consultant

Mr. Gábor Tiroler, International Child Health Unit (ICH), Uppsala

### Danlep

Mr. Anthony T D'Souza, Associate Corrdinator, New Delhi

### The Leprosy Mission

Dr. Cornelius Walter, Director, New Delhi

Leprosy Consultants:
    Dr R Ganapati, Director Bombay Leprosy Project, Bombay
    Dr CR Revankar, Deputy Director, Bombay Leprosy Project, German Leprosy Relief Association, Bombay

## REFERENCES (Documents Read by L.A.B.)

### General NLEP

National Leprosy Eradication Program; Appraisal Report and Project Proposal, Oct 1984, DANIDA

Leprosy Status Report 1985-86
Ministry of Health and Family Welfare, New Delhi 1986

Leprosy Status Report on Voluntary Organisations and NLEP, 1987

NLEP Guidelines for MDT in Endemic Districts, 1989

NLEP Operational Guidelines on Case Detection, Treatment, Follow-up and Reporting Forms. 1992

NLEP Status Report 1992

NLEP Facts and Figures 1992

### Independent Evaluations of NLEP

Leprosy NLEP Report of Independent Evaluation 1986

Leprosy NLEP The Second Independent Evaluation, Report 1987

Leprosy NLEP The Fourth Independent Evaluation, Report 1991

### SIDA-Documents Regarding Support to NLEP

(Some written in Swedish, some in English)

Project Memo January 4, 1978

SIDA-Decision, January 9, 1978 (C. Wahren)

Project document, April 1978

The Leprosy Control Program. Letter from SIDA-Stockholm to DCO (1978 07 14)

Comments on the design of the program, November 1979.

Draft memorandum on continued support during the period 1983/84-1987/88, April 12, 1983 by H, Ohlin, and letter from S. Abelin, New Delhi.

Project document, February 1984

Letters between SIDA, Stockholm and DCO, New Delhi,
May-December 1984

SIDA-Decision to channel support through WHO (in 12 districts) and
through Unicef (in 10 districts). December 21, 1984.

Reservations against the decision by Gudrun Hubendick and Ulla-britta Segersky,December 20 1984

Project memo for continued support to NLEP via WHO 1984-1988,
December 1984

Letter to D Haxton, UNICEF (1985 01 29) and report from meeting with WHO (1985 02 26)

SIDA-Memo about the suggested administrative post (May 31, 1985)

SIDA- Decision and Agreement with UNICEF (1985-07-10)
(Beslut om stöd till indiska lepraprogrammet via UNICEF)

Memo on the support to NLEP by Inese Zalitis. (Pm om SIDA-stöd till lepraprogrammet. I. Zalitis 1986-04-27, 3 sidor)

Memo for support to the health sector in India, February 1989
by A-K Bill

Project document, June 1990. (For the third agreement)

Project-Memo (1990-12-10); Support to
endemic diseases in India 1989-1984 by A-K Bill, SIDA Stockholm

Plan of operation for SIDA/WHO assistance
April 1991 - december 1991

Annual SIDA review meeting on progress in 1992. January 1993

## Consultant Assessments of SIDA's Support to NLEP

Comments on "Pilot project for intensification of leprosy control programs in India using multi-drug regimen" Report on a visit to Purulia and Wardha November 20-28 1979 by Göran Kronvall, 1979

Short term consultant evaluation of MDT in Wardha District, Mahrashtra, May 12, 1983 by Göran Kronvall, 1983

Comments on the development of the co-operation, January 7, 1984 by Göran Kronvall, Bioscand AB

Progress assessment of MDT under NLEP, December 27, 1984
by Göran Kronvall, Håkan Miörner and Peter Koren

Short term consultant assessment of SIDA supported MDT program in India, April 30, 1986 by Håkan Miörner

Report of a short term consultant assessment of SIDA supported MDT program, May 30, 1987 by Håkan Miörner and Karin Norlin

Travel report, December 1989 by Håkan Miörner and Karin Norlin

Tomas Lagerwall and Gábor Tiroler. Comprehensive Rehabilitation in India - a Community Based Approach for People Disabled by Leprosy and Others. March 1989

Gábor Tiroler. Rehabilitering för lepraskadade och andra handikappade i Indien, 1993-11-02

## Reports from MHFW to SIDA

Project document for 1990-1993 (9 pages, undated. Arrived SIDA June 26, 1990), including description of currant status 1.2)

Project Proposal, October 1990, including status report

Plan of operation for SIDA/WHO assistance April 1991-December 1991, including statistics about progress of MDT activities

Report for the Annual Review Meeting April 5 1993, including a current status of NLEP and budget proposal for 1993 (43 pages), March 16 1993

Sida assistance to NLEP, Status report, October 1993

## WHO Documents

Project Document, (9 pages) February 8, 1985

## UNICEF Documents

Multi-drug therapy project for leprosy control. Project design for project in India 1985-1989. UNICEF. May 1985

Progress Report for the Government of Sweden. Leprosy Control Program. Unicef August 1987

Progress and Utilization Report NLEP. Unicef, July 1988

Progress and Utilization Report on the MDT Project for leprosy control funded by SIDA. Unicef, June 30, 1989

Leprosy control. A report for Kap Study. Quest Qualitative Research, Bombay. Undated

## Danida Documents

NLEP. Appraisal Report and Project Proposal, October 1984

NLEP. Plan of operation, undated (1985?). Separate appendices for the districts Cuttac, Salem, Durg and Rajnandgaon.

Anthony T D'Souza. Adaptive role change: Affecting Community Health Culture and Salience in Health Service Delivery. An example of the NLEP South Arcot District, Tamil Nadu. Prepared for WHO IC Consultative Meeting of Leprosy Program Managers Colombo, Sri Lanka January 27-31, 1992

## World Bank Documents

Staff appraisal report, NLEP, India June 4, 1993

Memo and recommendation on a proposed credit to India for NLEP, June 10, 1993

## NORAD Documents

Norad Support for multidrug therapy program for the treatment of leprosy in Nellore, Kurnool and Prakasam Districts, Andhra Pradesh, India. Reports from short term consultancies in India November 12-18 1990 and February 28-March 6 1993 by Gunnar Bjune.

## Agreements

Agreement between Government of India and the Government of Sweden, April 24 1978

Specific agreement between GOI, WHO and GOS 1984/85-1988/89, Draft 1985-02-08

Agreement GOI, GOS and Unicef July 1, 1985- June 30 1988.
June 5, 1986

Extension of agreement Unicef-SIDA, May 31 1988.

(Decision about extension of agreement to June 1990
Decision about continued support to the program 1990/91-1992/93)

## Research

Ganapati, R. et al. Community based and integrated rehabilitation of leprosy patients. Indian Journal of Physical Medicine and Rehabilitation, Volume No 6, April 1993

Duggal, R. Jesani, A. and Gupte, M. Social aspects of leprosy. Finding from rural Maharashtra, Foundation for research in community health, March 1988.

Social sciences research and social action for better leprosy control. Papers and other documents presented at IAL National Workshop at Karigiri 14-15 March 1991

Sanjiv Kakar. The Politics of Segregation: Leprosy in Norway and India 1880-1900. Report. University of Delhi August 1993

Kopparty, S N M. Acceptance of deformed leprosy patients in the family: Some observations. Article in NLO Bulletin, Oct-Dec 1993

Thomas Lindgren. New Hope in leprosy and rural community development. Minor Field Study in India, June-August 1988

Ulla-Britta Engelbrektsson, Proposal for a study of leprosy patients and restoration of health in Nepal. Gothenburg, January 1991

Venkateswara Rao, K. Leprosy in rural India. Manak Publications, 1992.

## Miscellaneous

Report from the annual meeting f the voluntary organisations involved in the NLEP and state leprosy officers. New Delin November 6-18 1993.

A series of booklets produced by Danlep, Unicef, The Leprosy Mission India, and The International Lepra Mission

Social work education for developing human resources for leprosy control and rehabilitation by Dr DVP Raja, Director, Madurai Institute of Social Work, Undated memo,7 pages.

**R. GANAPATI & C.R. REVANKAR**

# INDEPENDENT EVALUATION OF SIDA ASSISTED NLEP MDT DISTRICT PROGRAM IN INDIA 1993-1994

## 1. INTRODUCTION

The Swedish International Development Agency (SIDA), a bilateral agency in agreement with the Government Of India, started its support to NLEP since 1978-1979. SIDA supported 19 endemic districts with prevalence rate more than 5 per 1000 population. These 19 districts, covering a population of 65 million (1991 census), are located in Tamilnadu (three districts), Andhra Pradesh (four districts), Maharastra (four districts), Gujrat (one district), Uttar Pradesh (one district), Bihar (one district) and Karnatak (two districts). In these districts, NLEP implemented the MDT program on a uniform pattern as described in National MDT guidelines. In these districts, District Leprosy Societies were established, as per the guidelines, to receive MDT funds and implement the program.

The program was monitored and evaluated regularly through monthly progress reports, review meetings and independent evaluations. Part time consultant leprologists' services as well as NLEP consultants' services were made available to all these districts.
The primary objective of the program was to detect all the leprosy cases and offer MDT and cure them to reduce the prevalence rate, bring down transmission to reduce the new case detection rate and to reduce the deformity rate among new cases. However, deformity care and prevention services could not be given equal importance considering the magnitude of the problem. Wherever possible, protective footwear and reconstructive surgical services were also provided.

## 2. TERMINAL EVALUATION

SIDA took up evaluation of these districts to find out the achievements and lacunae from an overall angle in 1993-94. Relevant epidemiological and operational data was collected from these districts by the evaluation team members (Dr. R. Ganapati and Dr C.R. Revankar). This data was processed to learn some of the important lessons. North Arcoat, Chengalpattu, Baroda and Wardha Districts were visited by Dr. R. Ganapati and Dr. C.R. Revankar so that they might have some impressions.

## 3. RESOURCES

### 3.1 Infrastructure

**Table 1: Infrastructure in 19 MDT Districts.**

| | NUMBER |
|---|---|
| 1. Leprosy Control Unit (LCU) | 83 |
| 2. Urban Leprosy Centre (ULC) | 55 |
| 3. SET Centre (Survey, Education, Treatment) | 216 |
| 4. Voluntary Organization (VO) | 60 |
| 5. Temporary Hospitalization Ward (THW) | 44 |
| 6. Rehabilitation Centre | 15 |
| 7. Reconstructive Surgery Unit | 15 |
| 8. Primary Health Care Centre | 1089 |
| 9. Leprosy Training Centre | 15 |

Infrastructural facilities available in the 19 districts are satisfactory considering the total population under Leprosy control. 60 voluntary organizations (VO) in these districts have played a significant role in achieving positive results. The facilities like Temporary Hospitalization Wards (THW), reconstructive and rehabilitation units and training centres are more than adequate to provide various facilities in these districts.

1,089 Primary Health Care Centres for a population of 65 million (one PHC : 60,000 population) can provide adequate facilities for passive case detection as well as future integration.

## 3.2 Manpower

**Table 2: Manpower in 19 MDT Districts**

| CATEGORY | SANCTIONED | AVAILABLE | | TRAINED | | UNTRAINED | |
|---|---|---|---|---|---|---|---|
| | | No. | % | No. | % | No. | % |
| 1. District Leprosy Officer (DLO) | 19 | 19 | 100 | 19 | 100 | Nil | -- |
| 2. Medical Office (MO) | 126 | 104 | 83 | 74 | 71 | 30 | 29 |
| 3. Non-Medical Supervisor (NMS) | 330 | 296 | 90 | 278 | 94 | 18 | 6 |
| 4. Non-Medical Assistant (NMA) | 1936 | 1567 | 81 | 1559 | 99 | 2 | 1 |
| 5. Laboratory Technician | 170 | 116 | 68 | 114 | 98 | 2 | 2 |
| 6. Physiotherapy Technician (PT) | 79 | 52 | 66 | 52 | 100 | Nil | -- |
| 7. Health Educator (HE) | 42 | 36 | 86 | 32 | 89 | 4 | 11 |

1. In regard to laboratory technicians and physiotherapy technicians, though forming an important part of the MDT program, only 67 - 68% were available. However, practically all had training in leprosy. These available physiotechnicians could be used to train field workers for delivering field disability care.

2. Only 74 (71%) medical officers, out of 104 available, were trained in leprosy control.

3. However, the manpower availability, especially DLO, MO, NMS and NMA, was more than 80%, which is quite satisfactory.

# 4. ACHIEVEMENTS

## 4.1 MDT Coverage

Before starting MDT, 446,479 cases were on record as receiving monotherapy, in 19 districts. When the MDT programe was started in 1981-82, no proper guidelines were available to the District Leprosy Officers. Hence screening of old cases was not done systematically. Even deletion criteria were not clear. During the "Cleaning of Registers" Operation in Bihar, Madhya Pradesh and Uttar Pradesh, deletion critera were made more clear as a result of the experience gained over the years and proper guidelines were given. All those cases who were not present at the time of assessment were also deleted. These factors account for enormous numbers being deleted (84%). This program was funded by SIDA in addition to MDT assistance for 19 districts. As this was a time bound and well planned and supervised program, work was done more systematically and reported. Simultaneously, new cases were also detected. As a result, a more accurate registered prevalence rate could be worked out before starting MDt. 20% of the 446,479 cases on record were of the multibacillary (MB) type. Since the beginning of MDT to November/December 1993, 637,023 new cases were detected. 17% were the MB type. The benefit of MDT was given to a total of 837,519 (old + new) cases.

Of 1,051,770 total cases (old + new) registered up to the end of 1993. This cumulative MDT coverage was 80%. 92% of the MB cases were brought under MDT. 647,368 (77%) patients completed the prescribed course of MDT.

The rest have yet to complete the program. Since the beginning of SIDA program, 989,027 cases were discharged as cured (mono- and MDT), deceased and as having left the control area, leaving a balance of 69,425 cases on record as of November/December 1993.

## 4.2 Registered Active Prevalence Rate

As a result of the MDT program, the registered active prevalence rate (PR) was reduced from 6.83/1000 to 1.07/1000 in 1993. The reduction rate was 84.33%, which is very significant and more or less similar to other districts. The current PR ranged between 0.32 and 3.06 per 1000. 15 districts have already reached PR of less than 2 per 1000, thus qualifying as low endemic districts.

Deogarh and Purulia districts have PR of more than 3/1000 even after nine years of MDT, which is probably due to local operational problems.

### 4.3 New Case Detection Rate (NCDR)

At the time of starting the MDT program, a total of 93,055 new cases were detected in these 19 districts. The annual new case detection rate (NCDR) was 1.43/1000. During 1993, 53,747 new cases were detected. The annual NCDR in 1993 was 0.83/1000. The mean reduction rate was 42%. All throughout the program, a total of 637,023 new cases were detected. It was expected to have a reduction in NCDR almost parallel to the registered prevalence rate. In reality, the fall was not appreciable. This was observed in all the districts.

This rate was ranging between 0.4 and 2.64 per 1000, as the duration of MDT program was different. An appreciable reduction was observed during the first six to eight years and subsequently the reduction was not so appreciable. The annual case detection rate became constant. Even though reduction was observed, the total new cases in absolute terms remain more or less the same. However, about 47% of the newly detected cases were mono-lesion PB cases, whose public health importance was negligible. The mono-lesion PB NCDR was 0.29/1000.

### 4.4 Proportion of Child Cases Among New Cases

Since the beginning of this program, a total of 175,939 child new cases were detected. 7,427 (4%) were the MB type. However, the child proportion did not show any decline. A total of 15,605 (16.7%) child cases were detected during 1993, showing an increase in case detection. The child proportion increased by 88%.

### 4.5 Proportion of Deformity (Grade 2) Cases Among New Cases

A total of 21,492 new deformity (grade 2) cases were detected, as per WHO (1988). The cumulative deformity rate among new cases was 3.4%. However, the deformity rate among new cases reduced from 6.4% to 2.4% (reduction rate was 62.5%) indicating that the new cases were detected at an early stage.

### 4.6 Proportion of MB Cases Among New Cases

In Indian Leprosy program, all MB cases are not smear positive, as per WHO grouping (1985). As per NLEP guidelines, even smear negative cases with 10 or more lesions (including nerves) are considered for MB regimen. 111,039 (17%) new MB cases were detected out of 637,023 new cases throughout the program. 38,114 (6.3%) MB smear positive cases were detected. (This data was not available from Srikakulam, Deogarh).

However the MB proportion reduced from 23.7% to 16% by the end of 1993. The reduction rate was 32.5%. However, this proportion varies from district to district, primarily due to different criteria being followed at different times. Smear positive new MB proportion reduced from 3.13 to 2.34 (reduction was 67.18%).

### 4.7 Incidence Of Reaction

The data available from six districts indicates that the incidence of reactions seems to be very low. This is perhaps due to the addition of Clofazimine to the MDT regimen.

### 4.8 Voluntary Reporting

After the introduction of MDT program, 35.1% of new cases reported voluntarily, indicating an increased awareness and popularity of the program.

### 4.9 Summary

The overall achievements are as follows:

| INDICATORS | BEFORE MDT | CURRENT | % REDUCTION |
|---|---|---|---|
| 1. Regd Prevalence Rate/1000 | 6.83 | 1.07 | 84.33 |
| 2. New case detection Rate/1000 | 1.43 | 0.83 | 42.00 |
| 3. Child Proportion % Among New Cases | 16.70 | 31.40 | +88.00 (increase) |
| 4. *Deformity Proportion % Among New Cases | 6.40 | 2.40 | 62.50 |
| 5. MB Proportion Among New Cases | 23.70 | 16.00 | 32.50 |

* Even though deformity rates (Grade 2) among new cases declined over a period of time, the total deformity cases (old + new) increased. In 14 districts, 33,833 deformity cases were recorded, which is a major post-MDT residual problem.

## 5. LEPROSY AMONG FEMALE POPULATION

Data available from Vishakapattanam and Wardha showed that 27,449 (36.8%) female patients were detected out of 74,544 new cases. In one of the districts (Baroda) 37.4% of the Grade 2 deformity cases were female patients.

## 6. DEFORMITY CARE AND PREVENTION

Routinely, health education is provided to all deformity cases regarding care of hands and feet. Data available from 12 districts showed that 31,315 patients were provided protective footwear. 1,397 deformity patients underwent reconstructive surgery.

## 7. POST MDT RESIDUAL PROBLEMS

### 7.1 Deformity Problem

The deformity (Grade 2) data among old monotherapy and old MDT cases was not available from all the districts. A special data collection made in 14 districts revealed that 20,666 (4.6%) deformed patients were recorded out of 446,955 registered cases.

Though the NCDR of deformity (Grade 2) among new cases decreased, the total prevalence rate of deformity (old + new) is high (0.82/1000). 33,833 (4.8 %) deformity cases were recorded in 702,323 (old + new) registered cases in 14 districts.

Though deformity rate among new cases has shown reduction, the magnitude of the problem would be quite high, requiring special deformity care and prevention programs using field technology after suitable task oriented training. If we consider Grade 1 (anaesthesia), this problem will increase, which will also require program attention from a point of protection of anaesthetic limbs.

However, deformity data from these districts does not include patients with various grades living in the leprosy colonies and leprosy homes. Before planning deformity care program, every effort should be made to update deformity data, including leprosy homes and leprosy colonies.

## 7.2 Relapse Problem

Over a period of time, 2,946 MDT relapses and 1,212 DDS monotherapy treated relapses were detected in 10 districts. Though the cumulative rate over this period is very low, this may reach an appreciable size in future. However, data on late reversal reactions from non of these districts is available, which is likely to be mistaken for post-MDT relapse due to inadequate training of NLEP workers.

# C. McDOUGALL

# ITINERARY

| | |
|---|---|
| 28th December 1993 | Travelled from UK to Delhi via Amsterdam. |
| 29th December to 3rd January 1994 | SIDA team meetings in Claridges Hotel, Delhi. |
| 3rd January | Travel from Delhi to Bhubaneswar, Orissa. Meetings with Joint Director of Health Services (Leprosy and Tuberculosis), WHO Consultant and the Assistant State Leprosy Officer. |
| 4th January | Travel from Bhubaneswar to Berhampur in Ganjam District. Meetings with district level officials of the National Leprosy Eradication Program (NLEP) for Ganjam. |
| 5th & 6th January | Evaluation, including field trips, of the work in Ganjam District. |
| Late 6th January | Travel from Berhampur to Srikakulam in Andhra Pradesh. Meetings with district NLEP officials and WHO Consultant for Andhra Pradesh. |
| 7th & 8th January | Evaluation, including field trips, in Srikakulam. |
| 9th January | Travel from Srikakulam back to Bhubaneswar in Orissa. |
| 10th January | Final discussions with WHO Consultant, State Leprosy Officer and Director of Health Services in Bhubaneswar. |

This concluded the district visits for SIDA. I then went on to assist the State Government in the District of Phulbani with teaching and training workshops for the implementation of multiple drug therapy.

| | |
|---|---|
| 25th January | Travel from Bhubaneswar to Delhi. |
| 26th January | Republic Day (national holiday). Stay in Delhi, writing this report for SIDA. |
| 27th January | Briefing with Ms. Gunilla Essner in the Swedish Embassy, Delhi, on my preliminary findings in the two districts. Courtesy call on Dr. B.N. Mittal, Deputy Director General (Leprosy), Directorate of Health Services, Delhi. |
| January 28th | Travel from Delhi to London and Oxford. |

## GANJAM DISTRICT IN THE STATE OF ORISSA

### Background Information

Ganjam is one of the current total of 13 districts in Orissa, soon to be subdivided into a total of about 30. It lies on the eastern sea border (Bay of Bengal) with Puri District to the north, Srikakulam in the State of Andhra Pradesh to the south, and Koraput and Phulbani to the west. The 1991 census gave a figure of 3,158,764 for the district population, about 40% of whom are of tribal origin. Ganjam extends to about 12,556 sq km and about 80% of the population live in rural areas.

### Basic Epidemiological Indicators

These are shown in the various tables of the Appendices. Although the situation is changing quite rapidly for the better (Ref. 1), Orissa has been highly endemic for leprosy for many years; seven out of its 13 undivided districts have, until recently, had prevalence rates of more than five per 1000 of the population. The State prevalence was 12.4 per 1000 in 1982 and it has now come down to 2.13 per 1000. Changes in incidence, disability and child rates are discussed below in appropriate sections.

### Staffing Structure

This is conventional, following the basic plan and guidelines in a series of publications from the Leprosy Division of the Directorate General of Health Services in Delhi (Ref. 2-6). No significant modifications have been made in Ganjam.

### SIDA Support For Multiple Drug Therapy (MDT) in Ganjam District

MDT was introduced in Ganjam, with SIDA support, in March 1983; it was the first district chosen in the State of Orissa and the fourth for SIDA support in the whole country, following Wardha in Maharashtra in 1981, Purulia in West Bengal in 1982 and Srikakulam in Andhra Pradesh in 1983. At the outset, Ganjam had a prevalence of 13.5 per 1000 and it was partly because of this high figure and partly because of the presence of a good infrastructure that it was chosen to be the first district for MDT in the State. The duration of the SIDA support in Ganjam, as for the other 18 districts, was essentially for the three years of the 'intensive' phase but in practice sometimes extended to four years. In the case of Ganjam, SIDA financial support was for several years channelled direct to the District Leprosy Officer and it was not until 1989 when the District Leprosy Society was formed that it went to the Chairman. In principle, Government of India support ceases, and reverts to support by the State Government, when the prevalence below two per 1000.

## Operational and Control Program Methodology

As with the staffing structure, this is conventional, following the Government guidelines already referenced above. The operational methodology has relied heavily on the establishment of circuits and the availability of reliable transport to carry a medical officer, non-medical supervisor, para-medical worker and driver, with organisation of patients at fixed treatment delivery points, ensuring that none had to walk more than 1 km in order to receive regular chemotherapy. The extent to which this system, devised at a time of high prevalence but still preserved in 1994 when the workload has fallen very markedly, is still viable and will be discussed below.

## Program of Work and People Contacted During the Evaluation

I was given detailed information by the Assistant State Leprosy Officer in Bhubaneswar and then accompanied throughout the visit to Ganjam by the Joint Director of Health Services (Leprosy and Tuberculosis) and the WHO consultant for the State of Orissa. We were met by the District Leprosy Officer and his supporting staff, who had organised an intensive program, including discussions at the DLO office and field visits to see a circuit in action. We also visited the Urban Leprosy Centre and the Leprosy Control Unit in Berhampur, where the doctors in charge explained their respective programs of work. During the circuit visit on the second day there was ample opportunity to examine patients, check the patient record cards and question the NLEP staff about their criteria for diagnosis, classification, ability to recognise reactions, follow-up of defaulters and disability prevention.

## Key Points From Discussions, Examination of the Records and Field Visits in Ganjam

Bearing in mind that most of the discussions, which were lengthy and detailed, took place between the Joint Director of Health Services, the WHO consultant for Orissa, the District leprosy Officer for Ganjam and myself, the following were the most important points which emerged:

### 1. Overall Contribution/Value of the SIDA Financial Contribution

Most senior staff, including the District Leprosy Officer, had first-hand experience of the period (1983-1986) during which money was channelled from SIDA, through WHO, to this district for leprosy work, but many others were completely unaware of what had happened in the past, did not specifically identify SIDA as a Swedish donor agency in India and had only a vague idea that either the Government of India, WHO or some other agency had provided money for the program. However, those who did identify SIDA as the main contributor in the early 1980's were unanimous in their praise and appreciation for what had been done. In common with the opinion of Dr. B.N. Mittal, Deputy Director General (LEP), Directorate General of Health Services, New Delhi, they emphasized that a large contribution of money had been made, without administrative delay, at a crucially important point in the early stages of MDT in India and that the results from Ganjam had greatly strengthened the Government case for extending the same strategy to other parts of India. Understandably, particularly in view of the diminished support for leprosy control work generally, including serious problems with the supply of vehicles (see below), many peopled interviewed were sad to hear that SIDA would be ending its support for MDT programs in March/Aril 1994.

## 2. Specific Contribution of SIDA to Medical and Operational Aspects

There is no doubt that the SIDA contribution enabled this district to get moving without delay on the implementation of MDT, including the 'preparatory' and 'intensive' phases and the removal from the registers of large numbers of patients, prior to MDT implementation, who did not qualify for chemotherapy. The operational indicators for this and the other 18 districts supported by SIDA are shown in the Appendices revealing, amongst other changes, that marked reductions in prevalence rates have occurred and that disability rates in newly detected cases are now very low (often zero). The child rates in Orissa generally appear to have risen, but it has to be recognised that large scale examinations of school children have increased greatly in recent years and that the ability of NLEP to detect early leprosy has almost certainly improved through the years. Additionally, there may well be an element of over- or wrong diagnosis in the recording of single (mono-) lesion cases in children (notoriously difficult to diagnose with certainty as being leprosy) due to the continuing of use of achievement 'targets' given to staff of the detection of new cases each month. Finally, in assessing the marked changes in disability rates it must be kept in mind that very large numbers of disabled patients were cleaned (screened) from the registers before MDT, and that these included a considerable percentage with Grade 2 (WHO) disabilities.

In summary, it is my impression that the SIDA contribution in Ganjam a) was greatly appreciated by those who saw it in action and b) almost certainly contributed a great deal to the establishment of the MDT strategy in the district thus helping to demonstrate that it could be extended to other parts of India. Its more precise effect on medical and operational outcomes is difficult, probably impossible to assess in precise terms at this stage (January 1994), mainly because so many years have passed since the period of SIDA financing.

## 3. Confirmation of Diagnosis

Particularly in view of the disappointingly slow decline in incidence/new case detection rates, even in districts which have implemented MDT for 5-8 years, I specifically asked about the process for confirming the diagnosis of leprosy. The answer is that in Ganjam 60% of all detected, referred or self-reporting cases are verified by non-medical supervisors, all of whom have had at least 10 years experience before promotion. The remainder are confirmed by a medical officer and/or an experienced para-medical worker. a small number of difficult or doubtful cases are seen by the WHO consultant (there have never been any district level consultants in Orissa). This process is probably satisfactory but a potentially weak link centres on the training and experience, if any, of medical officers (see below).

## 4. Screening Out (Removal From the Registers) Prior to MDT Implementation

In looking at the figures and overall results, SIDA should be clearly aware that the marked reductions in prevalence rates, not only in Ganjam and Srikakulam (see below), but also in the 17 other SIDA-supported districts, have in large measure been due to the removal from the registers of large numbers of patients, before MDT implementation. In Ganjam, the case load was 36,704 prior to MDT implementation, from which no fewer than 24,255 were screened out and removed from the registers. Furthermore, it is of considerable interest to note that a large number of those screened out were considered to have been cured by Dapsone monotherapy.

## 5. Disability Prevention and Management and Rehabilitation

Despite the official policy of the NLEP to combine these activities with case detection, MDT implementation, etc, there was general agreement during discussion in Ganjam that they had not been adequately addressed and that virtually nothing of significance, on the scale needed, had been achieved in rehabilitation. The reasons for this are complex and numerous, ut they include a) main emphasis on case detection, diagnosis and treatment with new and attractive regimens (sometimes provided in blister-calendar packs) b) a lack of systematic training and supervision of NLEP staff in the necessary procedures, all of which have been described in detail (reference 7 and 8) and c) a failure on the part of SIDA to insist that disability prevention and management were written into the agreement at the outset, almost as a condition of continuing support and that the defects identified by SIDA consultants through the years were remedied.

## 6. Medical Officers in the NLEP in Ganjam

The DLO drew my attention to the continuing and unsatisfactory situation with regard to medical officers posted into and out of the district. Of the nine who were in position about a year ago, all of whom had eventually received some training, every one has now been posted elsewhere and their replacements included doctors with neither experience nor training in leprosy. Ganjam has decided, very wisely, to reduce the period of training for medical officers from the usual three months to an intensive five days in future.

## 7. Vehicle Availability in Ganjam for Treatment Delivery and Supervision

As already mentioned, the leprosy program in this district is threatened by a shortage of roadworthy vehicles. All those in use are over ten years old, some 11 or 12. They are now down to a bare minimum and will not be able to maintain treatment circuits, school, general population, and contact surveys, as required by the NLEP, unless the vehicle situation is addressed.

## 8. Admission of Leprosy Patients to the Medical College Hospital, Berhampur

As on previous visits, I was impressed with the way in which leprosy patients are admitted to a 'leprosy ward' in the main hospital in Berhampur, where they are attended to by dermatologists, orthopaedic specialists and others as needed. Male patients only are admitted; the need for female admissions appeared to be very low, but they have occasionally been admitted to general wards (and they can routinely be admitted to the female wards of the Central Leprosy Training and Research Institute at Aska in this district). I was told by that there have never been any objections on the part of administrators, medical staff, nurses or the public to the admission of cases in the hospital at Berhampur.

## 9. Compliance and Regularity of Attendance for MDT

Based on recorded attendance rates, interviews with patients and surprise counts of tablets and capsules in villages, overall compliance has been assessed at well over 80% and often nearly 90%. The chemical 'spot' test for Dapsone in the urine has not been used nor has the colour of the urine been checked with 12 hours of supervised Rifampicin, for the presence of a typical red colour. Blister-calendar packs for MDT drugs were sometimes available (supplied by DANLEP) but were by no means regarded as essential to good compliance.

## 10. Voluntary Reporting of New Cases, Versus Detection by Staff

From previous levels of about 5%, voluntary reporting in Ganjam (and other parts of Orissa) now runs at about 50%, suggesting that there is a markedly improved attitude to seeking treatment on the part of the general public. the figure may in fact be higher, since there is a tendency on the part of some NLEP staff to 'convert' a self-reporting situation into one of active case detection, thus taking credit for the new case discovered.

### 11. Drug Toxicity from Dapsone, Clofazimine or Rifampicin

During these brief visits, despite enquiries, I received no information to suggest that toxic effects (ie. adverse effects on skin, liver, bone marrow, etc.) had been of significance. Anaemia is common in the rural areas of Orissa and might well have been accentuated by Dapsone, but this has not been investigated. The patients on the multi-bacillary regimen which includes Clofazimine did not complain of the typical reddish brown pigmentation of the skin which it produces or of troublesome gastrointestinal symptoms. In general it may be stated that in view of the fact that over four million patients with leprosy (many of them multi-bacillary) have been treated with MDT in India, remarkably few side effects have been encountered.

### 12. The Principle of 'Incentives' (Additional Money in SIDA Programs)

Considerable amounts of money have been spent on incentives for those taking part in the SIDA-supported programs. Those who have received this extra money have obviously been well pleased, but others looking at this element of the strategy more objectively have questioned its longer-term wisdom for a number of reasons. Although India has long had a 'risk-allowance' for staff working in leprosy, tuberculosis, cancer and radiology, the principle of an additional incentive to those taking part in MDT implementation has created some problems. Staff have been reluctant to accept transfer from an incentive to a non-incentive area and there have also been difficulties, for instance, in integrating leprosy work into the Primary Health Care system.

## SRIKAKULAM DISTRICT IN THE STATE OF ANDHRA PRADESH

Srikakulam is one of 23 districts in the densely populated State of Andhra Pradesh on the eastern coast of India between Orissa in the north and Tamil Nadu in the south. The language is Telugu, but English is widely spoken. The overall literacy rate is only 30% with significantly lower figures in women compared to men (as elsewhere in India). The population of Srikakulam is 2,314,442. The area is mainly agricultural; over 80% of the population live in rural areas.

### Basic Epidemiological Indicators

These are shown, together with those for Ganjam and the other 17 districts supported by SIDA, in the Appendices. As in Ganjam, following the screening out of large numbers of patients at the outset and the subsequent use of MDT on all registered cases, there has been a dramatic reduction in prevalence. The disability rate in newly detected (mainly mono-lesion) cases is very low (often zero). As already mentioned above, it is important for SIDA to appreciate that the initial screening of the registers had a highly significant effect on the total number of registered patients, before MDT started and that the fall in disability cases through the years is to some considerable extent related to the removal from the registers of many patients with disabilities.

## Staffing Structure

This has been conventional. Hardly any important modifications have been made in these patterns. Srikakulam has been unusually fortunate in that it is part of a high-endemic leprosy State (Andhra Pradesh) where there has been a long tradition of high quality leprosy work, including for instance, the proviso that all District Leprosy Officers must have at least five years experience before appointment to this level.

## SIDA Support for MDT in Srikakulam District

This was started in January 1983 with SIDA support and continued until January 1986. As with Ganjam and the other districts, the money went first to the District Leprosy Officer, later to the District Leprosy Society.

## Operational and Control Program Methodology

Again, this has been conventional throughout, following NLEP guidelines, as described above for Ganjam.

## Program of Work and People Contacted During the Evaluation

On arrival I was met by the District Leprosy Officer, Dr. Sastralu and also by Dr. Rajarao, currently DLO in Nalgonda, but previously DLO in Srikakulam for many years. We were joined by DR. B.K. Rao, WHO consultant for Andhra Pradesh and advisor to the NLEP in Delhi. Dr. Adeseshaiah, acting Program Manager for the State, came from headquarters in Hyerabad. We had lengthy discussions on all aspects of the program, which is outstandingly well documented and illustrated on a series of panels and charts in the DLO office. On the second day we visited a number of treatment points in a typical circuit and as in Ganjam, had ample opportunity to see patients, examine patient records and check the performance of staff.

Later I was taken to Pogiri Hospital about 40 km from the town of Srikakulam, which was built for leprosy work in 1962 by Danish Save the Children and transferred to Government administration in 1972. There are 50 beds and they were mainly occupied by male and female patients with recurrent foot ulcers , under treatment with ointment and bandages, followed by the provision, in some cases, of micro-cellular rubber chappels, but with limited acceptance and use by patients. This picture of weak and irregular availability of protective footwear for such patients is the rule in most parts of Orissa.

Key Points Arising from Discussion, Examination of Records and Field Visits in Srikakulam

## 1. Overall Contribution of the SIDA Financial Contribution

As for Ganjam, above, the officials met were unanimous in their praise and appreciation for what had been done; the SIDA backing was considered to have been invaluable, at a critical point in the development of the MDT strategy. In view of the long experience of the WHO consultant and Dr. Rajarao, this opinion must be considered to carry considerable weight, especially as both were familiar with events during the period of SIDA support.

## 2. Specific Contribution of SIDA to the Medical and Operational Outcome

It bears emphasis that the quality of work in this district has been so high throughout that it has been frequently analyzed and used to influence Government of India policy on leprosy control. However, in detailed and specific terms, my colleagues in Srikakulam admitted that it might be difficult in early 1994 to express an opinion on the contribution of the SIDA support in the early 1980's.

## 3. Temporary Hospitalization Ward Attached to the Main Hospital, Srikakulam

We visited this on the first day. There were 22 patients, mostly 60 years of age or more, with recurrent foot ulcers, under treatment with ointment and bandages. Facilities for protective footwear were uncertain. In a program which is in many ways outstandingly good, there were quite serious defects in the supply of protective footwear and, on a wider scale, it was admitted by those running the program that inadequate attention had been given to disability prevention and management. Rehabilitation does not seem to have been attempted on any meaningful scale.

## 4. Drug Supply, Quality Control and Compliance

Examination of drug stocks, usually kept in pad-locked metal cabinets, revealed good supplies of Dapsone, Clofazimine and Rifampicin, together with 5mg tablets of Prednisolone for the treatment of reactions. There were also bottles of aspirin and paracetamol (for nerve pain, etc) and ferrous sulphate tablets (for anaemia). The origin of the MDT drugs was mixed; many had been manufactured in India, others came from Ciba-Geigy in Switzerland and there were some blister-calendar packs supplied by DANLEP. Drug supply and distribution appeared to be satisfactory with no 'unexplained' losses, notably of Rifampicin. I was not able to obtain information on quality control (including for instance, bio-availability studies) but it was the general impression that none had been done.

Compliance, using the indicators already mentioned above, ranged from 80-90%.

## 5. Monitoring, Assessment and Supervision by SIDA

The people I met in Srikakulam, most of them highly experienced, expressed some surprise at the lack of systematic assessment and monitoring of the results of SIDA support through the years. At least one official considered that a detailed assessment should have been carried out about three years after the start of SIDA financial support. Various SIDA reports, made available to the evaluation team when they met in late 1993 in Stockholm, describe visits made by SIDA consultants, with recommendations, but regrettably with little or nothing by way of follow-up. The absence of an effective disability prevention and management program, over a period of years, is particularly unfortunate and should have been corrected at an early stage, perhaps as a condition of continuing support.

## 6. Present and Future Operational Strategy in Srikakulam

My overall impression from this brief visit is that an enormous amount of high quality work has been (done) through the years and that this was greatly helped by the SIDA contribution in the early 1980's. The district now faces a situation, however, in which the transport situation is weak, many of the vehicles being old and heavily repaired, thus threatening the established pattern of circuits and out-patients supervision. Furthermore, the workload has fallen dramatically and there is a need to develop new strategies and patterns of work to fit these changed circumstances. This should include detailed training and instructions for existing staff on disability prevention and management, particularly as many of them are no longer fully occupied. The picture with regard to national policy on disability management and rehabilitation is complicated by discussions currently under way in Delhi involving financial backing by the World Bank. Until this becomes clear it is difficult to make practical proposals for improvement in these activities in the two districts dealt with in this report, and the future involvement if any of SIDA in rehabilitation programs, for instance, in Srikakulam or Wardha.

# REFERENCES

1. Pattnaik, P.K.B. Multiple Drug Therapy in Ganjam District, Orissa. Achievements from 1983 to 1993. Leprosy Cell, Directorate of Health Services, Bhubaneswar, Orissa, January 1994.

2. National Leprosy Eradication Programme in India, 1987. Guidelines for Multi-Drug Treatment in Endemic Districts. Leprosy Division, Directorate General of Health Services, Ministry of Health and Family Welfare, New Delhi, India, 1987.

3. Ditto Revised Version, 1989.

4. Mittal, B.N. National Strategy for Elimination of Leprosy in India. Indian Journal Of Leprosy, volume 64(4), 1992.

5. National Leprosy Eradication Programme. Operational Guidelines on Case Detection, Treatment, Follow-up and Reporting Forms. Leprosy Division, New Delhi, as above, 1992.

6. National Leprosy Eradication Programme in India. Revised Guidelines for Multi-Drug Treatment in Endemic Districts, 1993. Leprosy Division, New Delhi, as above.

7. National Leprosy Eradication Programme in India (Care of the Cured). Guidelines for Disability Care and Rehabilitation, 1993. Leprosy Division, New Delhi, as above, 1993.

8. International Federation of Anti-Leprosy Associations (ILEP). Prevention of Disability. Guidelines for Leprosy Control Programmes. ILEP Medical Commission, Leprosy Control Discipline, 1993.

9. Krishnamurthy, K.V. Protective Footwear for Leprosy Patients with Sole Sensory Loss or Ulceration of the Foot. Correspondence, Accepted for publication, 1994, Leprosy Review.

# M. PEAT

# REPORT FOR THE SWEDISH INTERNATIONAL DEVELOPMENT AUTHORITY (SIDA) ON A VISIT TO BOMBAY TO EVALUATE THE MULTI-DRUG THERAPY (MDT) PROGRAM IN INDIA

The visit was organized by Dr. R. Ganapati, Director of the Bombay Leprosy Project, and Dr. C.R. Revankar, Deputy Director. The visit was organized to provide a view of the various aspects of the project, from community programs to inpatient services.

* Department of Preventative and Social Medicine
  Lokmanya Tilak Memorial Medical College
  SION (Computer Centre)

* Vocational Rehabilitation Centre for the Handicapped
  (Ministry of Labour)

* Leprosy Ward
  Adam Whyllie Hospital
  (Indian Red Cross)

* Dermatology Out-patient
  Grant Medical College
  J.J. Hospital

* Urban Health Centre
  L.T. Memorial Hospital
  (adjacent to DHARAVI)

* Community Leprosy Program
  DHARAVI (slum area)

* Shramik Vidyapeeth
  Vocational Training Centre
  DHARAVI

This is an excellent integrated program ranging from institutional care to community based services focusing on integration, employment and acceptance.

## Bombay Leprosy Project - January 5th
### Leprosy Ward, Adam Whyllie Hospital

This 21 patient unit is available for patients who require inpatient care (foot ulcers and reaction) and is also part of a drug trial research program. With an out-patient (MDT) service also being available, the unit is run by paramedical workers who have had six months training in administration, finance and drugs. Public support is required for the continuation of the service.

A member of the leprosy project has completed a study on attitudes toward leprosy, a copy of which has been requested. In addition, a related study of attitudes has identified that relatively 'poor' attitudes toward leprosy exist in the senior level of the medical profession, although younger physicians are more knowledgable, making major policy changes a problem.

A review of both patient and financial records demonstrated a high level of competency, with the financial records having been kept with great detail. This indicated very professional staff and high quality leadership.

A discussion of the use of drugs other than MDT, including Predisolone, indicated that the use and application of these other drugs is generally not well understood or consistently applied.

In the in-patient service, the financial support of each patient is 196 rupees per month while the actual cost per patient is 750 rupees per month. All eight areas in Bombay get SIDA support for incentives, clinic register/stationing, PT aids, training of field workers and health education. The project pays the difference.

## Grant Medical College - January 5th

This is Bombay's oldest medical college and is highly regarded both nationally and internationally. A visit was made to:

- the outpatient (leprosy) clinic
- the laboratory - skin smear services
- rehabilitation services
    - ADL and splints
    - development of a disability assessment protocol
- footwear program

This is an excellent example of a highly integrated approach to leprosy management into a broader clinical program, with the clinic and service being located in a comprehensive dermatology program. The disability program in this unit was also particularly impressive, the technical level and competency of the personnel being excellent.

### Urban Health Centre - January 5th
### L.T. Memorial Hospital

The hospital provides a clinical teaching program in community medicine. The hospital is adjacent to the major slum area of DHARAVI, which is occasionally referred to as 'Asia's largest slum'. From this centre a visit was made to two patients who are part of the leprosy community based rehabilitation program; both lived, worked and were integrated into the social and economic life of the community. One patient was a member of a family who had a 'small scale pot making industry' and demonstrated appliances which enable him to adapt tasks to his abilities and so function effectively in the work environment. The second patient was a vendor of sugar cane and also demonstrated an understanding of disability, using hand splints to enhance function. Both patients, their families and their communities demonstrated the value and potential rewards of a commitment to integration.

### Shramik Vidyapeeth, January 5th
### Vocational Training Centre

This centre was needs oriented for both the community and the patient, providing training in such crafts as screen printing and tailoring, with emphasis on self-employment skills. The patients also included physically disabled from other causes, making it an example of integrated rehabilitation. The agency is supported by a number of organizations such as the government, the Bombay Leprosy Project and the Lions Club. Some of the major and most popular courses include Beautician (1st), Hand Painting (2nd) and Wireman (3rd), with others such as welding being sponsored by industry. The average age of the participants is 15-30 years of age, with a 50% ratio of men to women. Leprosy patients are integrated into the vocational training.

### Department of Preventative and Social Medicine - January 5th
### Lokmanyo Tilak Memorial Medical College, SION

This facility concentrates on computer program development, supported by DANIDA, having one computer plus its accessories and two personnel, a programmer and an operator. The objective is to become the central statistical resource for leprosy for all of Bombay District.

### Vocational Rehabilitation Centre for the Handicapped

R. Narasimham is the Senior Superintendent of this facility, which is similar to 17 others in India under the control of the Ministry of Labour. Leprosy patients are less than 5% of the total number at this facility, however, it is a model of integration.

**J. WATSON**

## TERMS OF REFERENCE

The evaluation shall comprise but not necessarily be limited to the following aspects:

- the epidemiological and public health impact of the Multi Drug Therapy programme related to control and eradication of leprosy.
- the utilisation of funds and the cost-efficiency of the programme.
- the infrastructure and logistics of the Swedish programme and how it may be adapted to the epidemiological changes in each area in relation to the PHC structure.
- the quality of drugs and their handling as well as side effects and their treatment.
- the social effects of the NLEP with respect to attitudes among the public and with respect to community participation in the programme.
- the disability index, according to the guidelines of WHO, e.g. the relationship between newly detected cases and the ones with disability among those, and the prevention of the dehabilitation of new cases in the future as well as the possibilities to rehabilitate those physically and socially disabled.
- to assess what data is available to describe the baseline situation in 1986, its adequacy for programme planning and outcome measurements, and its utility for administrative and auditing purposes
- to describe programme inputs; to describe programme outputs; to describe programme outcomes; to assess whether objectives were achieved.

The lessons to be learned from the NLEP for the future operation of the programme. Clear recommendations should be made on the aspects of the programme, including possible other donors for future financing.

## ITINERARY AND MEETINGS HELD

1. December 28th/Arrive Delhi midnight

   December 29th - January 2nd/Evaluation team discussions in Delhi

2. January 3rd/Fly Delhi-Calcutta

   a.m. Met in Calcutta by the State Leprosy Officer, Dr. Chatterjee. We travel together by train to Purulia, arriving shortly before midnight.

   January 4th/Day 1 : Purulia

   1. Meet the DLO and National and State Leprosy Consultants.
   2. Visit Kuda DDP (Drug Delivery Point).
   3. Visit DLO Office. Discussions with Varanasi team and consultants.
   4. Evening meal hosted by Dr. Ghosh. He and Dr. Mahapatra are to depart tomorrow morning.

   January 5th/Day 2 : Purulia

   1. Visit Kanditah DDP, under Balarampur LCU (Govt.).
   2. Visit Chatu Hasa DDP, also under Balarampur LCU (Govt.).
   3. Visit Balarampur Control Unit Office, the State HQ of the Gandhi Memorial Leprosy Foundation.
   4. Discussions with the CMO and with team members at the circuit house.

   January 6th/Day 3 : Purulia

   1. Visit DDP Purulia Block-I in Pichasi sector.
   2. Discussions with CMO, and Consultants at Circuit House.

   January 7th/Day 4 : Travel to Bankura District

   1. Visit the Regional Training and Research Institute of the Central Government and the State Government Leprosy Hospital which is on the same compound.
   2. Discuss training facilities.
   3. Participate in the monthly meeting of senior Leprosy Control staff of Bankura District.
      Return to Purulia.

January 8th/Day 5 : Purulia

Discussions with Dr. Rajan Babu, Mrs. Margaret Mahato and Dr. Kiran at the TLM Referral Hospital in Purulia.

January 9th

Travel by TLM jeep to Tatanagar and thence by overnight train to Varanasi.

**3.** January 10th/Day 1 : Varanasi

Arrive 8.30 a.m. by train from Tatanagar.
Driven to Government Tourist Guesthouse.

1. 9.30 a.m. Meet consultants and colleagues and visit 3 DDPs.
2. p.m. Visit Varanasi District Leprosy Office to see data and have discussions regarding the programme.

January 11th/Day 2 : Varanasi

Visit more DDPs.

January 12th/Day 3 : Varanasi

Visit more DDPs. Examine 6 former patients having a disability problem at the DLO office. Go to airport to await flight to Delhi, but this is cancelled. Overnight in Varanasi at airlines' expense.

January 13th/Day 4 : Varanasi

All morning awaiting postponed flight. Late afternoon, fly Varanasi to Delhi, too late for the planned meetings with Ms. Essner of SIDA and Dr. Mittal of MOPH. Thus change ticket from 13th to the next KLM flight on 16th from Delhi to London via Amsterdam.

January 14th : Delhi

a.m. Discussions with Mr. Jan-Olov Agrell, Counsellor and Head, and Ms. Gunilla Essner, Senior Programme Officer, Development Co-operation Office (SIDA).
p.m. Discussions with Dr. Mittal, Director of NLEP.

January 15th : Delhi

a.m. Discussions with Dr. C. Walter, Director, The Leprosy Mission, India.
p.m. Discussions with Dr. Boudewijn F.A.M. Peters, Chief Adviser, Danida Assisted National Leprosy Eradication Programme.

January 16th : Depart India

Catch early morning KLM flight Delhi to London.

## 1. INTRODUCTION TO PURULIA VISIT

The population of Purulia District was 18,53,801 at the time of the 1982 census and had risen to 22,17,423 by the time of the 1991 census. The area covered is 6,259 square kilometres, 6193 sq.km being rural and only 65.6 urban. The district has a strong component of tribal people. It is bounded to the north, south and west by Bihar State. Thus there is much inter-State migration. Some leprosy patients live in Purulia, West Bengal (WB) and work in Bihar.

MDT was introduced to Purulia, with SIDA support, on 1.2 82. The intensive phase lasted until 1985 under the direction of Dr.Ghosh who was transfered to the district from the State office. SIDA funds were paid directly to the district. A SIDA official came in 1985 and closed the local SIDA account. By 31.3.85., the intensive phase was complete and there was gradual handover of responsibility to local leprosy staff under Dr.Mahapatra as DLO. SIDA funds were then sent from Delhi to the district direct, and banked in a District Society account. SIDA support was terminated on 31.3.91.

There are 5 Leprosy Control Units plus 1 Urban Leprosy Unit in the district. Several Voluntary Organisations collaborate in the work: The Leprosy Mission conducts urban clinics and training courses and operates a referral hospital with reconstructive surgery facilities. The German Leprosy Relief Association and the Gandhi Memorial Leprosy Foundation run rural leprosy control units and there is a leprosy centre named Nabakushanipas.

Many patients in Purulia district have been cured and many new patients have been identified. Thus the programme has shown definite success. The leprosy prevalence in 1982, presumably prior to the cleaning of registers, was over 30 per 1,000 and has been reduced to 3.06 per 1,000. However despite the reduction in prevalence rate, the recent impact of the programme on the incidence rate and the new case detection rate (particularly MB cases) gives cause for some concern. In 1993, up to November, there were 2,500 new cases, greatly exceeding the new patient target set by the NLEP of 700 new cases. Staff look forward eagerly to the results of the stratified sample survey in the district which is scheduled to commence in February 1994.

|  | Active Cases | MB Prev | Prev. Rate | New Cases (N C) |  |  | NC detection rate |
|---|---|---|---|---|---|---|---|
|  |  |  |  | MB | PB | Total |  |
| 1982-83 | 27,823 | 4.24 | 14.69 | 1,936 | 2,760 | 4,696 | 2.48% |
| 1983-84 | 34,057 | 5.21 | 17.75 | 2,392 | 5,882 | 8,274 | 4.29 |
| 1984-85 | 30,744 | 4.36 | 15.81 | 889 | 4,182 | 5,071 | 2.58 |
| 1985-86 | 26,791 | 2.70 | 13.60 | 729 | 5,716 | 6,445 | 3.22 |
| 1986-87 | 19,599 | 1.98 | 9.83 | 598 | 5,390 | 5,988 | 2.94 |
| 1987-88 | 12,619 | 1.72 | 6.25 | 760 | 4,621 | 5,381 | 2.59 |
| 1988-89 | 12,040 | 1.76 | 5.89 | 893 | 4,574 | 5,467 | 2.59 |
| 1989-90 | 10,024 | 1.79 | 4.82 | 1,046 | 3,029 | 4,075 | 1.90 |
| 1990-91 | 9,023 | 1.77 | 4.13 | 1,323 | 2,878 | 4,201 | 1.92 |
| 1991-92 | 8,485 | 1.70 | 3.83 | 1,184 | 2,571 | 3,755 | 1.69 |
| 1992-93 | 7,576 | 1.58 | 3.35 | 1,128 | 2,704 | 3,832 | 1.69 |
| To Nov. 1993 Only | 7,054 | 1.52 | 3.06 | 777 | 1,790 | 2,567 | 1.11 |

| Numbers of active | MB | PB | Total |
|---|---|---|---|
| On record February 1982 at the start of MDT: | 6,251 | 17,994 | 24,245 |
| On 31.3.91.at the termination of SIDA support: | 3,828 | 5,193 | 9,021 |
| On 30.11.93 ...............................: | 3,499 | 3,555 | 7,054 |

Total number of new cases detected 1982-November 1993: 59,752
Total number of cases inducted into MDT (pre + new): 58,431
Total number of cases discharged from MDT as cured: 47,791

New case finding indicators are shown in the table below. During field visits some problems in recording of deformity were noted.

| Year | Total N C | Children among N C |  |  |  | Deformity Gd.2 in N C |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  |  | MB | PB | Total | % | MB | PB | Total | % |
| 1982-3 | 4,696 | 68 | 773 | 841 | 17.90 | 394 | 230 | 624 | 13.29 |
| 1983-4 | 8,274 | 120 | 1115 | 1,235 | 14.93 | 395 | 548 | 943 | 11.40 |
| 1984-5 | 5,071 | 51 | 1016 | 1,067 | 21.04 | 192 | 405 | 597 | 11.77 |
| 1985-6 | 6,445 | 43 | 1044 | 1,087 | 16.87 | 177 | 323 | 500 | 7.76 |
| 1986-7 | 5,988 | 67 | 985 | 1,052 | 17.57 | 87 | 151 | 238 | 3.97 |
| 1987-8 | 5,381 | 65 | 890 | 955 | 17.75 | 92 | 94 | 186 | 3.46 |
| 1988-9 | 5,467 | 80 | 918 | 998 | 18.25 | 100 | 96 | 196 | 3.58 |
| 1989-90 | 4,075 | 89 | 636 | 725 | 17.79 | 49 | 51 | 100 | 2.45 |
| 1990-1 | 4,201 | 96 | 697 | 793 | 18.88 | 97 | 42 | 139 | 3.31 |
| 1991-2 | 3,755 | 106 | 570 | 676 | 18.00 | 71 | 32 | 103 | 2.74 |
| 1992-3 | 3,832 | 112 | 649 | 761 | 19.86 | 65 | 37 | 102 | 2.66 |
| To Nov. 1993 | 2,567 | 84 | 456 | 540 | 21.04 | 30 | 13 | 43 | 1.74 |

The next table shows gradual improvement in attendance rates, but still 24.30% non-attendance overall, highest non-attendance fortuitously being amongst PB patients.

| 31st Mar | Cases on record |  |  | Cases on MDT |  |  | % of attendance |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  | MB | PB | Total | MB | PB | Total | MB | PB | Total |
| 1987 | 3,960 | 15,639 | 19,599 | 3,013 | 6,822 | 9,835 | 39.56 | 50.79 | 47.35 |
| 1988 | 3,483 | 9,136 | 12,619 | 2,925 | 5,788 | 8,683 | 76.06 | 66.13 | 69.48 |
| 1989 | 3,614 | 8,426 | 12,040 | 3,201 | 6,425 | 9,626 | 75.91 | 56.32 | 62.84 |
| 1990 | 3,712 | 6,312 | 10,024 | 3,472 | 4,533 | 8,025 | 86.69 | 56.27 | 69.43 |
| 1991 | 3,828 | 5,193 | 9,021 | 3,649 | 3,766 | 7,415 | 91.91 | 67.65 | 79.50 |
| 1992 | 3,935 | 4,550 | 8,485 | 3,764 | 3,307 | 7,017 | 87.4 | 67.79 | 77.76 |
| 1993 | 3,580 | 3,996 | 7,576 | 3,507 | 3,205 | 6,712 | 87.71 | 62.55 | 75.70 |
| 30th Nov. 1993 | 3,499 | 3,555 | 7,054 | 3,433 | 2,779 | 6,212 | 75.36 | 71.82 | 73.77 |

Reasons given by consultants and DLOs for numbers of new cases exceeding national estimates were as follows:

- "Phased implementation of MDT. Only 80% on MDT as yet.
- Statewise, out of 19 districts only 5 are currently on MDT.
  1 district may have around 8-10,000 accumulated patients.
  There is much inter-District and inter-State migration.
  It is planned that 7 more go on to MDT during 1994.
  6 others are embarking on preparatory cleaning of registers and should go to MDT in 1995.
- Late diagnosis due to the stigma.
- Some loss of the initial enthusiasm seen when MDT was first introduced. In the initial period of the campaign patients expectations were high in regard to their own felt needs, e.g. ulcers and deformity. They don't know what leprosy bacilli are ... cannot see when they go. Thus currently their enthusiasm is low.

Case Holding

The next table shows numbers discharged from treatment: Cured or "otherwise". However the term "otherwise covers patients who died and moved together with those who failed to complete their treatment course. Thus numbers who failed to complete treatment are not known. During the year 1993 up to November, 13.46% of discharges came into the "otherwise" category.

| Years | Disch. total | Disch. cured | Disch. otherwise MB | PB | Total | % | Relapsed |
|---|---|---|---|---|---|---|---|
| 1982-83 | 144 | 0 | 144 | 0 | 144 | 100. | |
| 1983-84 | 299 | 12 | 287 | 0 | 287 | 95.98 | |
| 1984-85 | 3,562 | 3,217 | 294 | 51 | 345 | 10.72 | 0 |
| 1985-86 | 6,569 | 6,083 | 345 | 141 | 486 | 7.40 | 2 |
| 1986-87 | 7,358 | 7,012 | 207 | 139 | 346 | 4.70 | 14 |
| 1987-88 | 7,382 | 6,643 | 156 | 583 | 739 | 10.01 | 42 |
| 1988-89 | 5,357 | 4,954 | 129 | 274 | 403 | 7.52 | 68 |
| 1989-90 | 5,978 | 5,248 | 239 | 491 | 730 | 12.21 | 28 |
| 1990-91 | 5,091 | 4,416 | 274 | 401 | 675 | 13.26 | 45 |
| 1991-92 | 4,248 | 3,765 | 209 | 274 | 483 | 11.37 | 99 |
| 1992-93 | 4,277 | 3,748 | 286 | 243 | 529 | 12.37 | 68 |
| To Nov. 1993 | 3,112 | 2,693 | 202 | 217 | 419 | 13.46 | 38 |

## 2. PURULIA DISTRICT VISITS AND CONSULTATIONS

### 2.1 Personnel who are to be involved in the evaluation visit programme were met on January 4th/Day 1 Purulia

Discussions were held with the Chief Medical Officer of Purulia District (CMO), Dr.K B Sinha, at the Purulia office and Collectors House, on several occasions.

**Personnel participating in the evaluation visit:**

State Leprosy Officer, Dr.Chatterjee
Regional Leprosy Consultant (WHO) for WB, Bihar, Sikkim and Manipur Tripura, based in Calcutta,
Dr.K C Das.
  Dr.Das preceeded Drs. Rao and Mittal as Deputy Director General of Health Services (leprosy), MOPH & Family Welfare, Govt. of India and actually created the Leprosy Division.
Consultant Leprologist for the District, Dr.Halder,
  Ex-Director of Health Services for WB. Was SLO in 1982 when the SIDA-supported MDT programme commenced in Purulia.
District Leprosy Officer (DLO) for Purulia District,
  Dr.Buddhadev Roy, whose special interest is ophthalmology.
DLO Bankura, Dr.M K Biswas.

**For day 1 only:**

Technical Officer at commencement of SIDA programme in 1982,
  Dr.Ghosh. Now Leprosy Consultant for Bardaman district in West Bengal (WB).

Ex-DLO from 1985, Dr.Mahapatra,
  who took over responsibility for the SIDA programme from Dr.Ghosh at the time when SIDA direct supervision was replaced by local supervision. Dr. Mahapatra is now a Demonstrator at Bankura Medical College.

### 2.2 Visits were paid to 4 Drug Delivery Points DDPs):

- The 1st DDP was at KUDA, 1.5 hours drive from Purulia, was manned by an NMS having 30 years leprosy experience and a PMW having 16 years leprosy experience. 33 patients were listed as currently on treatment now, 11 of them MB.
- The 2nd DDP visited was at KANDITAH, and was held in frontof a PHC which was in a very dirty condition. 28 patients were listed for treatment, 18 of them MB. Both NMS and PMW had many years of experience, despite which their work was seen as very poor. The MO responsible for supervision of this DDP is Dr.Debasish Roy. (See Staff: MO notes).

- The 3rd DDP visited briefly was CHATU HASA DDP. This was conducted in a rural area and in the open with 3 beds as furniture. The NMS and PMW appeared competent.
- The 4th DDP visited was PURULIA BLOCK-I DDP in Pichasi sector and was held in front of a PHC clinic. The MO, Dr.S K Dhara, has a Diploma in Dermatology and is hoping to take up a Dermatology Post, though none fixed as yet.

DDP circuits are on specified days of every month, even if the day falls on a Sunday or holiday -- though extra special public holidays are exempt.

### 2.3 A visit was made to the Balarampur Leprosy Control Unit Office (State HQ of the Gandhi Memorial Leprosy Foundation)

Discussions were held with their Project Officer Mr. Sudhakar Bandyopadhyay.

The Foundation serves a population area of 2,65,000 in 20 sectors set in 4 zones. The prevalence rate is 2.14% and they currently have 564 patients on treatment. The project staff includes 20 leprosy workers plus 10 support staff. The 4 NMSs each have motorcycles. The PMWs live in the sectors in which they work and travel by bicycle ... maximum distance 8 km.. The workers spend 2 days per month taking clinics, 4 days following up and motivating patients who did not attend or have problems, and the remaining 20 days in their designated activity to identify new patients and reduce stigma.

### 2.4 The fourth day was spent in the neighbouring district of Bankura:

- to visit the Regional Leprosy Training and Research Institute (RLTRI) and state referral hospital at Gouripur, and
- to participate in a monthly district leprosy meeting and compare reports of activities with those in Purulia district.

## THE PRINCIPAL ISSUES RAISED BY THE VISITS WERE AS FOLLOWS:

## 3. THE IMPACT OF SIDA INPUT FROM 1982-1991

Several of the experts accompanying the visit had led the Purulia programme at the time of the SIDA-backed MDT initiative. All greatly appreciated SIDA's role in providing both the stimulus and the funding for the initiation of the MDT programme.

The experience of the Consultants was seen to be helpful to the DLO. Dr.Halder travels with the DLO for 5 days per month and Dr.Das, as regional adviser, visits several times in a year.

Funding problems were being experienced after the withdrawal of the SIDA support:

- for vehicle POL (petrol,oil,lubricant) and maintenance,
- for non-MDT-drugs, such as Prednisolone,
- for travel allowances,
- for office rent, etc.

The standard of MDT in districts with and without SIDA funding are expected to be similar. In practice, due partly to a serious lack of trained MOs and cessation of SIDA funds in Purulia, the neighbouring Bankura district programme seemed to be functioning more efficiently. The Bankura DLO also had public health experience and management gifts, and an almost full quota of MOs to supervise LCUs, several with some years of experience.

It was disappointing to find that disability prevention target-setting and activity had seemingly not be encouraged in any way by the SIDA input, despite prevention of disability being one of SIDA's stated aims.

## 4. DRUG SUPPLY

### 4.1 MDT Drug Stocks at District Level

When SIDA took up the funding of Purulia, the supply of drugs was good. However there has sometimes been dearth of drugs in recent years, in particular periodic dearth of clofazamine for period of several months at a time. Rifampacin had been unavailable in the district for 3/12. According to the DLO, difficulties experienced in getting drug stocks were caused by:

a) Communication gaps, e.g. the storeman not knowing when stocks are available. The system is for the DLO to send an indent for MDT medicines to the SLO who, according to his stock, allots medicine. If not in stock the SLO advises the DLO when stock arrives. The responsibility for arranging to have supplies collected lies with the DLO who arranges for the storeman to go to Calcutta, usually once or twice per month.

b) Delay in collection. It is 400 km Calcutta to Purulia by road. Sometimes vehicles break down or are full with goods for other departments such as family planning. Transport staff get more TA if they travel more which is an incentive for more journeys.

c) Litigation between Government and the drug company at national level caused some clofazamine supply problems.

SLO Recommendation: That MDT drugs be sent direct to the DLO as was the system when SIDA was involved.

### 4.2 MDT Drug Stocks System Within the District

- The LCU MO keeps the main stocks. The NMS keeps sub-stocks.
- The NMS comes to the clinic and gives needed drugs to the PMW.
- The PMW can stock Dapsone but not Rifampacin or Clofazamine.

In theory there should be an NMS at every MDT clinic ... only when he is on leave should he give the medicine to the PMW. However, the NMS may not always be able to get to all clinics. Thus the PMWs must always contact the NMS before their circuit days .. and will receive packaged medicines for expected patients if the NMS will be unable to go to the DDP.

The second DDP had been without Rifampacin for 9 months, compared with 3 months at other DDPs, due to a local organizational problem.

### 4.3 Prednisolone and Other, Non-MDT Drugs

Prednisolone can be obtained through the Central Medical Stores (CMS) in Calcutta. For the past 2 years the policy has been to decentralise. Now 38 drugs and other materials such as gauze, cotton wool are listed as recommended for normal Government usage. There are other lists of less commonly needed drugs including Prednisolone. The CMO has to choose how to allocate district funds. Bankura still receives 12,000 (0.12 lakh) rp per annum in special SIDA funds and can use these to buy extra drugs, whereas this extra funding has ceased in Purulia. See "Other drugs, C iv" on p.75 in NLEP Guidlines. The drug company selected by the CMS to supply Prednisolone has an agreement that supply must be at the agreed rate of 28rp per 100 tablets X 5mg.. However, the market price is currently 40 rp..

Hence the drug companies are reluctant to sell to the CMS. Thus Prednisolone is often not available through leprosy staff when prescribed. Patients needing it are advised to buy for themselves, but it is often not available for sale in the market and, where it is available, patients see it as expensive.

Any leprosy program stocks of Prednisolone are kept and prescribed by the MO. Consultants say that on average each LCU has 20 patients needing Prednisolone at any one time. Roughly 10-15 recent paralyses are diagnosed per annum. The usual starting dose given is 30 mg.per day, tapered off at a speed guided by improvement (mainly in pain levels). Higher dosage, e.g. 80 mg.per day, can be given to hospitalised patients. Two patients seen at the 4th DDP had acquired their nerve lesions while receiving treatment. In neither case had Prednisolone been available from the LCU. The patients had bought insufficient quantities, only enough for 1 month.

## 5. MULTI DRUG THERAPY

Fixed duration course orders were given in September 1993, though are not yet being implemented. The DLO noted that they would have liked to be allowed to continue MDT for 4 years for patients in whom signs of disease activity are perceived. According to NLEP guidelines defaulters should restart treatment if defaulting for more than 1 month (PB) and 2 months (MB). In practice there are longer gaps.

Treatment registers were well kept in three of the DDPs. In the 2nd DDP the register was very disorderly with no lines drawn and many absentees shown.

According to district data, currently 73.77% are regular, 26.23% irregular. There was good attendance at the 4th DDP but a lot of absentees in particular at the 2nd, some of them being young, e.g. one boy aged 14 and one young lady aged 24. Several had taken treatment for several months before defaulting. One female who defaulted after 3 months said: "I'm much better now. The leprosy will clear itself". Only one of several defaulters discussed was reported as giving a medical reasons for stopping, in the form of repeated ENL over 2 years.

Numbers who complete their MDT course are reported on p.a.. However the data does not show percentages of patients who default rather than completing their treatment course as numbers of the former are combined with numbers who died or moved under a general heading "otherwise". Bankura district have added separate defaulter information.

Dr.Mahapatra: Prevention and care of disability would be a motivating factor for patients, encouraging attendance regularity. The effectiveness of the leprosy programme needs to be clearly perceived by patients.

# 6. GENDER ISSUES

## 6.1 Numbers of male patients seen far exceeded female patients

Gender-orientated data is not available at district level, though could be gleaned from patient cards. It seem important to check new case finding indicators, compliance indicators and disability/dehabilitation indicators for male/female differences. Were there differences, reasons behind them would need to be investigated and the implications for programme management.

## 6.2 Social effects of deformity

- A girl affected by deformity will rarely marry.
- If a married, leprosy-affected lady develops deformity prior to having children, she is likely to be turned out of the house.
- She will probably return to her mother if she accepts her, but otherwise may become a beggar unless able to work.
- If she has had children before developing deformity, she will be allowed to stay but will be neglected.
- In contrast the man is "the lord of the house" so is not so treated. His wife is obliged to stay with him.

Tribal ladies are evidently more free and treated with more equality, working side by side with their husbands in the fields. It is accepted that they sometimes reject and leave husbands, as was the case with one male, tribal patient seen whose wife and child had moved in with his brother's family.

## 6.3 Could ladies be PMWs?

There was much discussion regarding the possibility of having female PMWs but this seemed to be impractical on the grounds:

- that babies need attention = the main difficulty for travel,
- that few ride bicycles, and
- that "it may not be safe" for a woman to travel alone in the countryside.

On the other hand some staff said that many Multi Purpose Workers are female, and they travel, though less than leprosy workers.

### 6.4 Privacy

The 1st DDP was held in a very public place on the pavement in front of shops, on a busy street. Another was in a secluded, rural spot. Two DDPs were beside PHC centres where some privacy could have been sought. At the 4th DDP, reminded by our presence, the LCO suggested that several ladies be examined in a quiet room in the PHC and this was arranged. Apart from this no attempt was observed to provide privacy for ladies being examined. Although a PHC should be allocated a female worker as well as a male worker, there was a vacancy at this centre.

Culturally it is difficult for ladies to be examined at all by men. They only allow their bodies to be examined:

- up to their knees, and
- their backs by lifting up their blouses from behind.

At the first DDP an attempt was made to examine in public a girl, aged around 10, suspected of having leprosy. Examination was incomplete, for example excluding buttocks, because conducted by males and in public. Female patients seen were asked to get their mothers to check for patches and to report on these the next month. Staff say that PMWs may visit their homes, but even then it might be difficult for a male PMW to examine them, though a male doctor would be allowed to make a fuller examination. To speak would also be difficult for shy ladies, when surrounded by a crowd of male onlookers.

Lack of privacy is likely to discourage ladies from attending.

### 6.5 Female representatives on the panchayat are very committed, know the women in their area and can be very helpful

## 7. LABORATORY FACILITIES/SMEARS

### 7.1 Checks for smear quality

Smear cross checking was carried out 2-3 years ago:

a) 2 leprosy lab workers checked the same slides There was 25-30% variation.
b) Findings were cross checked with the Leprosy Mission Purulia laboratory. There was nearly 30% variation.

The DLO would like to use The Leprosy Mission services more often for cross-checking but lacks funds to pay for this service.

### 7.2 Laboratory facilities

There are laboratory facilities in 3 of 5 control units in the district, manned by 5 laboratory workers altogether. The DLO reported that only 4 of the 8 sanctioned microscopes are currently working. Field programme staff say that they lack access to laboratory facilities other than for skin smear examinations and MI, and to X-ray facilities.

### 7.3 Smears and classification

At the second DDP:

- Two smears taken during the clinic both included blood.
- Many patients had had no smear taken or were overdue.
- According to the SLO and Advisers:
  - 3 patients classified as MB should have been PB
  - 1 patient had relapse wrongly diagnosed.

## 8. FUNDS

### 8.1 Funding during the SIDA support period

DLO: Up to 1990 the district received 5 lakhs rp.from the central government (including SIDA funds). This included 12,000 rp.per vehicle p.a. for maintenance, incentives and cycle/ motorcycle allowances. At that period the vehicles could be well maintained.

### 8.2 Funds owing from the SIDA period

However 1.5 lakh rp.for Travel Allowances (TAs) is owing from the SIDA period, for staff incentive payments due for the first three months of 1991, just before the incentives stopped from April. Lack of this back-payment is a dis-incentive for staff, however well-motivated.

### 8.3 Funding since the cessation of SIDA funding in April 1991

The District Society was established during the 1991-2 financial year to provide funds for maintenance of the work, e.g. for travel allowances, vehicles, electricty and telephone. However, there have been district funding problems since 1991, reflecting national funding problems. The DLO describes State Government funds as meagre ... 4-5000 rp for contingencies for each of the 6 leprosy control units.

Funds for travel allowances (TAs): 2-3,000 rp p.a. are allocated to each LCU to cover TA costs incurred by 20 PMWs, 2-3 NMS, 1 MO plus clerical and other staff (e.g., laboratory technicians and peon messengers); however, the DLO reports that annual requirements are nearer 10,000 rp. minimum. Available funds, as they arrive, are given out in settlement of claims in order of their submission. Priority of permission to incur TAs is given to MOs and clerical staff going to Calcutta for office works and to staff attending monthly staff meetings.

State funds for maintenance of vehicles and POL are proving insufficient. To help with current funding problems, The Leprosy Mission have released a fund of 3 lakhs rp for vehicle POL for the year 1993-94 and have sanctioned 25,000 rp for repairs.

PB cards were seen being used for MB patients at some DDPs due to lack of funds for replacement of MB cards.

## 9. HEALTH EDUCATION

### 9.1 Health education activities in Purulia

This is seemingly not organised systematically in Purulia District, though staff do undertake some teaching, especially giving talks at schools and through discussions with people who show interest in learning about leprosy.

School surveys are preceeded by talks for scholars and teachers, teachers being encouraged to report any patches that they see. A 16mm movie projector and film are available at State level for use in giving health education in schools, at seminars etc..

Education of panchayat members is found to be helpful. The panchayat system is strong. Its members are elected by the community and include one third women. A village of 5,000 people will have 2 representatives, by law 1 should be male and 1 female. The females on the panchayat are very committed and know the women in their area. Panchayat representatives, having been shown pictures of early signs of leprosy, may go with a PMW to find suspected new patients. Despite these activities, Purulia seems to have a much less active and structured programme of health education than Bankura. There is no evaluation by means of questionnaires to determine whether or not health education has improved understanding of leprosy or acceptance of those affected by it.

### 9.2 Health education activities in Bankura

Bankura has the advantages of having 7 MOs in addition to the DLO, many of them having several years of leprosy experience. Bankura also receives strong support from a Leprosy Mission health education team in Bankura.

Notes on Bankura 1993 activities:

- The Leprosy Mission have a Health Education unit in Bankura district which moves in the field according to a schedule and which responds positively to DLO requests for help.
- The leprosy team have met all panchayats and Integrated Child Development Schemes (Women's groups caring for children up to age 6 and for females aged 14-44 = child-bearing age ... immunizing, nutrition etc. 3/12 training courses). They teach early signs of leprosy and list treatment dates for all panchayats, women's groups, health workers, MOs, some medicine shops. The groups then refer cases. At PHCs, a notice has been painted on the wall to give leprosy treatment dates and 4-5 salient features of leprosy together with the advice "don't fear" and "it may not be leprosy".

- A written appeal was sent to all head teachers describing salient features. Use slides.

  When films are required, ask TLM who are very helpful.

Special Drives in Bankura during the year:

- Stratified random survey No.93I/O to estimate the present load in the district and give indirect propoganda to the NLEP.
- Meetings with all the 19 Panchayat members: 19 at samity level and 171 at anchal level.
- Painting notices on the health point walls X 116 at the BPHC/PHC/SHC/SC level indicating salient features on leprosy and "pulse calendar" (clinic timetable)
- Distribution of pulse calendar to all concerned.
- Distribution of MDT Q and A to all PH Centres and local practitioners
- Meeting with all Health Staff of the 22 Blocks in the District and ICDS staff with slide projector.
- Meeting with PHC Indoor Nursing Staff and Teachers of the GNN Training School of BSMC&H, Bankura.

Voluntary reporting percentages in Bankura had gone up since an extensive health education campaign was commenced in 1992 ... from 37% in both 1990 and 1991 to 42% in 1992 and 52.35% up to Nov.in 1993.

### 9.3 Health education activities carried out by the Gandhi Memorial Leprosy Foundation

Gandhi Memorial Foundation activities in one unit of Purulia District are largely centred on Health Education. Foundation staff are undertaking a systematic study and programme, though

being less busy than most Government projects allows time for this. Patients were subdivided initially into 3 groups:

- Group A (10,000 population) focusses on contact survey (6 staff).
- Group B (10,000 population) focusses on mass survey (6 staff)
- Group C (65,000 population) focusses on community health education (3 staff).

Groups A and B were reversed when the next survey was carried out. 152 of the 402 new patients detected in 1993 were found through some sort of contact survey, including 24 through case contacts and 3 through schools surveys. However groups with a health education focus were found to have the best case detection rate. The % of new cases having disability has lessened from 20.4% in 1977 to 2.7% (11 of 402) in 1993, ALL of the latter being from outside their area. There is a huge migration of people (mostly tribal) coming from Bihar as a result of a new dam construction in Bihar, and many patients are migrant workers travelling to plant rice for 2/12 p.a. and to harvest it for another 2/12. Despite this the MDT compliance rate is 96%. Tablet counts have verified compliance in 1,281 out of 1,421 MB patients and 2,373 out of 2,728 PB patients.

The Gandhi Memorial Foundation programme health education activities include many slide presentations, puppet shows and talks. Slides can be used as long as there is electricity or if their jeep is working so that they can transport their generator, puppets, etc). Groups covered include:

- 397 schools have been covered in 1 year,
- Panchayat meetings,
- National Cadet Corps, Scout and Guide meetings,
- Women's groups.

The film and puppet show have to be transported by jeep, as does the portable generator when slides are used in situations in which there is no electricity. However their jeep has been out of action for 1 year and they are hoping that someone will donate a new one.

### 9.4 Communication with patients

Communication was generally kind but almost exclusively "one way", with patients not usually being asked for their views atall but rather "advised". At the second DDP The attitudes of both NMS and PMW towards patients was very brusque and would not encourage either confidence or regular attendance.

The 1st DDP was outside a PHC centre and seating for waiting patients could have been arranged. At the 4th DDP patients were seated both when waiting and when examined. Lack of sensitivity to ladies' privacy is commented on under gender issues.

## 10. STAFF AND TRAINING

### 10.1 Staffing levels

The table below shows the staffing position during three periods: in 1986-87 during the SIDA support period, in 1991-92 at the close of the SIDA support period, and currently. Note particularly the shortage of trained Medical Officers to supervise field work and of physiotherapy technicians to assist in action to control disability.

At the same time, due to the significant reduction in case load there is now over-staffing of PMWs and NMSs: 91 PMWs were responsible for treatment between them of 3,832 patients on treatment 1992-93, i.e., on average only 42 patients per PMW, 274 per NMS and 1,277 per MO. One PMW encountered during the visit now conducts only two DDP circuits per month.

Field staff have of course other important tasks such as health education, surveys, counselling and tracing of defaulters. However a serious problem is the paucity of MOs trained in leprosy to supervise the work and maintain quality of service.

| POSTS: S = sanctioned<br>E = existing<br>T = trained | 1986-87 | | | 1991-92 | | | To Nov.1991 | | |
|---|---|---|---|---|---|---|---|---|---|
| | S | E | T | S | E | T | S | E | T |
| District Lepr.Officer | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| Medical Officer (MO) | 6 | 4 | 3 | 6 | 4 | 2 | 6 | 3 | 2 |
| Non Medical Supervisor | 17 | 13 | 1 | 16 | 12 | 11 | 16 | 15 | 14 |
| Para Medical Worker<br>*26 under training Jan.'94 | 99 | 91 | 24 | 96 | 88 | 56 | 96 | 91 | 85* |
| Laboratory Technician<br>**1-2 weeks orientation | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5 | 5** |
| Physiotherapy Technician | 6 | 1 | 1 | 6 | 1 | 1 | 6 | 1 | 1 |
| Health Educator | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| Driver | 6 | 6 | | 6 | 4 | | 6 | 5 | |
| Clerk | 7 | 5 | | 9 | 8 | | 9 | 8 | |

## 10.2 Doctors' activities and problems

The DLO: The DLO travels for 5 days per month with Dr. Halder and would like to travel for 5 other days per month on his own. In practice he manages 2 extra days rather than 5, totalling 7 days per month in the field. He cannot go more often because of fuel costs. He is sometimes given other health duties, or has to do office work in Calcutta with the SLO.

MOs: Vacancies, lack of training and in some cases lack of motivation were serious problems in Purulia district. Work at the 2nd DDP in particular suffered from lack of supervision.
The majority of MOs evidently stay for only 2-3 years, though one stayed for 20 years and one for only 6 months. At present 3 other of the MOs have dual charges, none of them having had with leprosy training and none really interested in leprosy.

Example: Dr. Debasish Roy's leprosy work is additional to his work at a health centre, and is theoretically for 2 days per week, for supervision of 3 sectors having between them a total of 20 DDPs. During his 3 months of leprosy work he says that he has visited only 4-5 of the 20 DDPs. To cover all DDPs would require 15-16 travel days. He seemed to see his main leprosy job as conducting monthly staff meetings + undertaking administrative tasks. Dr.D Roy says that he needs leprosy transport but could have used the PHC vehicle to make more visits had he deemed it important. The DDP nearest to his office is 16 km distance, the next a further 8-9 km.. Dr. D. Roy started the leprosy work 3 months ago and is expecting to be transferred elsewhere after 2-3 months, to be nearer to his wife who works 100 km.away. The doctor who will replace Dr. D Roy will evidently be a full-time leprosy doctor. Another MO, Dr.S K Dhara, has a Diploma in Dermatology and is hoping to take up a Dermatology Post, though none has been fixed as yet.

According to the Consultants, there is a serious motivation problem in regard to doctors, many not liking to work in leprosy programmes because:

- there is no future in the work,
- they gain narrow experience not useful in their future careers,
- they are pressured by the system to take post-graduate training, and
- there is some stigma still attached to staff working with leprosy, though this situation is improving.

There was discussion with consultants and DLOs as to what action,if any, might improve doctors' willingness to work in leprosy programmes. Their suggestions were:

- "Reserve some post-graduate places for doctors who have persevered in leprosy work for 3-5 years"

- "For the India Medical Council to sell the concept that leprosy training is valued as important as a preparation for careers in dermatology, surgery, ophthalmology and neurology."

Question: "How much training in leprosy is given during doctors' training courses?"

- Dr.Debasish Roy said that his general medical training in Calcutta included a total of 15 days on dermatology, little on leprosy.
- During Community Medicine Training Courses in Bankura, Dr. Mahapatra gives 10 lectures on leprosy but says that this is atypical. He tries to arrange for doctors see patients during the training but often fail due to transport problems.
- The basic textbook on community medicine includes 7 pages on leprosy written by Dr.Parke who worked in A.P. State. Cochrane's book on leprosy is in the library.

The SLO plans management training for 50 in Calcutta, for the 18 DLOs, senior NMSs, superintendents of leprosy hospitals, physiotherapy staff and laboratory technicians.

### 10.3 Non-medical staff

NMS: The consultants consider that NMSs need supervision:

- because they are selected for the job by seniority rather than ability, and
- because they are not trained or skilled in management tasks

Of 15 NMSs in Purulia district, Dr.Halder and the LCO reckon that 7 work satisfactorily and 3 poorly. 4 are new and learning. One NMS post has been vacant for the past 7-8 months.

Regarding the appointment of a District physiotherapist, a SLO stated: "One has been appointed for leprosy work but has no leprosy programme and so is doing orthopaedics". A leprosy hospital can appoint a physiotherapy technician, however a State Leprosy post must be filled only by a 3 year physiotherapist.

### 10.4 Training undergone by present staff

Both Dr. Dhara and Dr. Chatterjee have worked in leprosy for 3 years. Both underwent leprosy training only after they had worked for nearly one year. At present 3 other of the MOs have dual charges, none of them having had leprosy training. One has worked in leprosy for 3-4 months, a second who has also worked for a few months expects to be transferred in February or March 1994. The Manbazar MO has worked in leprosy for nearly 2 years. It is expected that he will take over the job of Zonal DLO and thus is likely to receive leprosy training.

From November nearly 25/26 PMWs were sent at the same time, and at short notice, for 4/12 PMW training. Some are new. Others have worked for 4-5 years. The DLO had requested that the 26 staff be trained in 2 batches. To take so many at once is bound to create problems in managing the field programmes. Had 1-2 staff been taken at one time from one LCU, the sample survey planned for 1993 could still have been conducted.

The Bankura State Referral Hospital physiotherapist says that he has had no training in leprosy and showed no knowledge of basic leprosy physiotherapy tasks.

## 11. SURVEYS AND VOLUNTARY REPORTING DATA

Prior to the introduction of MDT, a first, rapid mass survey was carried out. In July 1988 a second round of general population survey was started, continuing for the next 3 years ... and followed up by tracing of those who had been missed.

Since that time, mid-1991, there have sometimes been special surveys. School surveys are always done. However the DLO is not aware what percentage of schools/contacts have been covered. He reports that approximately 57% of new cases are identified during surveys of one sort or another such as school/contacts/general. Numbers of patients found through different surveys: unknown.

Percent of new cases reporting voluntarily to LCUs is as follows:

| | | |
|---|---|---|
| 1982 .......... | | Pre 1982 MDT, 1st rapid mass survey |
| 1987/88 = | 54% | |
| 88/89 | 41%... | In July '88, 2nd round of gen.pop.survey |
| 89/90 | 36% | continuing for next 3 years |
| 90/91 | 54% | followed by tracing of people missed. |
| 91/92 | 48% | |
| 92/93 | 45% | Since that time there have sometimes |
| 93/Nov.94 | 48% | been some special surveys. |

1993 survey plans:

- PMWs were asked to do school and contact surveys during the rainy season, to be completed by Puja (November).
- Stratified,random surveys scheduled for November 1993 were postponed until February 1994 because 26 PMWs were sent for 4 months of training.

From 1994 the DLO plans to organise yearly school and contact surveys more consistently.

In the Gandhi Memorial Foundation programme, 152 of the 402 new patients detected in 1993 were found through some sort of survey, including 24 through case contacts and 3 through schools surveys. However, intensive community health education proved more cost-effective in identifying new cases.

**There is seemingly an urgent need for a sample survey,** similar to those used in the initial survey conducted by Dr.Chowdhary. At the termination of the SIDA contract after 8 years there was no repeat survey. Thus no-one knows the real position at present. Dr.Das estimates the cost of a stratified sample survey as 2.5 lakh rp (including TAs). The 1994 plan is to examine a total of 10% of the people to be examined, stratified according to prevalence, MB/PB and tribe/caste groups.

## 12. VEHICLES

Four of the seven sanctioned vehicles, all diesel jeeps, are currently on the road.

Up to the end of 1990, the DLO had funds for vehicle maintenance and POL (petrol, oil, lubicants). At that period the vehicles could be well maintained with the help of SIDA funds of 12,000 rp per vehicle p.a.. For the past 2-3 years there have been funding problems. There are 6 sanctioned vehicles for 6 Govt. units plus one SIDA vehicle, which is still in running condition.

- Out of the 6 Government vehicles, only 3 are currently in running condition, 7-8 years old. The other 3 vehicles need beteen then at least 50,000 rp.
- The SIDA vehicle also needs bodywork repairs, etc. costing 10,000 rp.
- Two vehicles have been out of order since 1991.

Thus a total 60,000 rp needed.

Currently a Government fund is available for repairs and, in theory, for running costs. In practice the DLO has had to turn to The Leprosy Mission which donated 300,000 rp towards vehicle fuel (permitted for repair only up to 25,000 rp) and motorbike and cycle allowances as well as for health education and some general medicines for the year 1992-93.

## 13. DISABILITY CONTROL AND REHABILITATION

### 13.1 Disability and dehabilitation data

There is almost no information available regarding numbers of present and former patients in the district who are disabled and/or otherwise dehabilitated. Rough information regarding deformity in MDT patients could be collected from individual patient forms. However sensation records, as checked during field visits, were not reliable.

a) **WHO deformity grading:**
is ascertained from the body charts but several mistakes were observed. For example 4/11 MB patients at one DDP were recorded as having grade 0 deformity, but two of the four did have disability, one each grade 1 and 2

b) **Testing and recording of sensation and strength:**
Quality of sensory testing and recording was inadequate. For example, in one patient staff had recorded complete loss of dorsal sensation on a hand, with no loss of palmar sensation whereas, in fact the patient had an ulnar nerve lesion with complete sensory loss down the ulnar border of the hand and little finger (both aspects) and three finger clawing. A second patient had a dropfoot which was recorded plus an insensitive sole which was not recorded.

c) **Patient cards were checked for signs of disability at two DDPs**
Of the 36 patient cards checked at the 2nd DDP visited, 12 cards (33%) showed disabilities:

- 1 showed unilateral lagophthalmos,
- 3 showed complete loss of hand sensation (2 bilaterally, 1 also showing loss of all fingers and both thumbs),
- 7 showed had foot sensory loss (2 bilateral, 2 dorsal sensory loss only, 1 also had unilateral loss of toes),

Of 37 who attended for treatment at the 4th DDP during the day of the visit (not all present at the time of the visit), 7 who were examined were found to have disability:

- Most were young and at serious risk of worsening disability.
- Two had acquired their nerve lesions whilst on treatment
- The disability grade had worsened since diagnosis in at least 3 patients, 2 due to new nerve lesions and 1 due to a wound in an insensitive foot. Worsening in some other patients would not result in a change in grade.
- 2 required and wanted surgery, 1 for footdrop and the other for ulnar, 4-finger clawing.

### 13.2 Action to control disability and dehabilitation

It was clear that staff lack training and expertise in action to prevent worsening of disabilities and to rehabilitate.

#### a) Social problems.

In the 4th DDP a young woman was diagnosed as having leprosy, but the fact that her father had been cured seemed to give her confidence and render her unafraid, which was encouraging.
In contrast another young unmarried woman, cured and with no disability, came to one DDP very worried lest she be getting a new leprosy skin patch. This was a false alarm, but it is important that staff check with her and her parents lest the former diagnosis is causing problems, for example affecting her marriage prospects. Attempts need to be made routinely to identify and overcome any such problems.

At the 4th DDP a youngish male with highly active leprosy from a very poor tribe came for treatment. Dr. Das took the trouble to visit his home and village, to examine and reassure contacts and identify the family problems. The patient's wife and children are no longer sleeping with him and are presently living in the same compound but at the house of his brother and family and this problem needs attention to halt social dehabilitation.

#### b) Preservation of nerve function where deteriorating.

Many staff had not been taught that Prednisolone could encourage sensory recovery as well as strength recovery and would not therefore have prescribed Prednisolone for "silent", recent sensory loss.

Two patients seen at the 4th DDP had acquired new nerve lesions during treatment. In neither case had leprosy staff been able to supply Prednisolone. Thus both patients had agreed to buy some for themselves, but only for 1 month instead of the widely accepted minimum for new nerve lesions of 3 months. One of the two was a young man who began treatment on 6.11.90. with no disability was found to have reaction on 11.12.91: pain and tenderness in nerves in all 4 limbs and feet oedema. At that time his dorsiflexors became weak (VMT grade 4), which was noticed, and he suffered then-unnoticed loss of sensation under his right forefoot and left heel. At the time he was given a referral letter for The Leprosy Mission hospital, but did not go due
to the expected cost. No Prednisolone was in stock at that time so he was advised to buy. He bought enough for low doses for one month ... 15mg X 15 days + 10 mg.X 15 days. He reported that there was useful improvement in foot strength and reduction in oedema, but sensory loss remains.

A third, cured patient reported at the zonal centre with loss of sensation and strength incurred 3 months previously. Prednisolone was prescribed.

ENL reaction had been treated with Clofazimine, Paracetomol and Prednisolone when available or if the patient could buy it on the market.

### c) Lifelong self-care of eyes and limbs affected by peripheral nerve dysfunction.

Simple advice regarding exercise and avoidance of injuries is given to patients with nerve lesions and some have obviously been helped by this advice. A limited number of patients buy protective footwear from the Leprosy Mission Hospital. However care-problems revealed by neglected wounds and callus are seemingly not being identified and solved and worsening of impairment was seen in a worrying number of patients. For example:

- One patient had both an MH3 ulcer and a short middle toe, neither of which were recorded on his initial body chart, i.e. his deformity has worsened, his disability grade remains at 2. He thinks that MDT will solve his foot problems and is not taking foot care, even though the PMW can advise that he should use protective shoes and do passive and active foot exercise.

- A lady had a partial dropped foot (EDL was paralysed) and an MH1 ulcer which she says has been healing and recurring for 2-3 years. Is wearing Hawaii slippers costing 12 rp. Needs protective footwear costing about 60 rp. Zinc tape has been advised but is expensive. Possibly needs surgery.

- A younger male patient had had a dropfoot for 2 years. Sole sensation normal. No other disability. Needed a dropfoot support and surgery. Stays at grade 2.

- A male aged 35 was on the verge of becoming seriously dehabilitated. He had:

    - unilateral lagophthalmos (approximately 5 mm gap on tight closure and some exposure keratitis),
    - bilateral ulnar/median claw hand with a serious fingertip injury caused by collecting stones from the ground using bare hands (staff will now try to get him a rake),
    - bilateral loss of sole sensation with bilateral heel ulcers and a unilateral 1st metatarsal head ulcer.
    - A cured patient with bilateral hand sensory loss, left ulnar paralysis and one wound on each hand. Mentally slow but accompanied by an intelligent man who seemed able to identify probable cause of left hand thumb base wound as grasping a tool. The NMS to visit his home/try to determine cause and avoidance plan. Stays disability grade 2.

- One man had an open crack in the heel area. He says "cracks heal in summer" and is taking no care. When asked what he had learnt he said "oil", but had no idea of soaking and rubbing and possesses no oil. Demonstration of skin care proved possible at the clinic. Disability grade 1 on diagnosis. Now grade 2.

- A middle-aged lady with sensory loss in medial 3 toes and 1st to 3rd metatarsal heads and an imminent crack at her big toe IP joint. Disability grade 1 on diagnosis and now.

- A 30-year old lady with left forefoot anaesthesia of the sole and an MH2 ulcer (possibly also diabetic). The ulcer appeared around June 1993 following a painful blister. Since then it had sometimes healed and sometimes recurred. She says that she usually wears Hawaii slippers but is currently wearing hard sandals with a prominent nailhead under MH1. A hammer was obtained and the nail head flattened. Teaching re footwear and wound care were given. Disability grade was 1 on diagnosis, 2 now.

- A 24-year old male having bilateral ulnar nerve lesions, sole sensory loss and an open heel crack. Disability grade was 1 on diagnosis, 2 now.

Simple field measures and/or protective footwear would help a number of the above.

**d) Protective footwear is needed by all with sole sensory loss. For example:**

- A young man whose soles were largely insensitive, but who was not referred to The Leprosy Mission for protective footwear due to a mistaken belief that even very poor patients had to pay for these.
- One patient was wearing shop-bought, enclosed, plastic shoes which have given him an injury medial to MH1.
- The 30 year-old lady with forefoot sensory loss and a wound recurring since June 1993 urgently needs the footwear.

**e) Reconstructive surgery**

- A young man with ulnar paralysis and 4 finger clawing who needs surgery when slight PIP joint stiffness and extensor muscle inefficiency affecting index and little fingers have been overcome. Exercises taught. Disability grade 2 at diagnosis and now.
- Two men needed surgery for a complete dropfoot and one lady for a partial dropfoot.

It seems important that the DLO and Consultants talk with The Leprosy Mission referral hospital superintendent to clarify what services the hospital is able to offer to patients unable to afford services and how application should be made. Dr.Das suggested that the Government might be able to offer a contribution to costs, such as 100-200 rp towards an operation for a patient unable to contribute.

### 13.3 Funds for welfare activities

In theory each LCU should receive 5,000 rp p.a. from the State Government, paid through the Society -- 50% of it for health education and 50% for welfare activities (protective footwear being the priority). In practice, Purulia District receives 4-5,000 rp p.a. to be used for health education only, i.e. The State Government is **not** able to replace SIDA funds. The District Society's only funds in 1993 were the 3 lakh rupees given by The Leprosy Mission.

No use being made of loans offered by banks and for which staff in some areas are helping their patients to apply for. Staff say that there are social workers who might be able to help do this if they knew what to do. (Notes: Dr.Peters of DANLEP is making up a list of resource agencies. The Leprosy Mission would be able to give advice).

### 13.4 Examples of earlier West Bengal rehabilitation schemes

Dr. Das described three "care after cure" schemes in West Bengal, one of them for TB patients:

- Care by the family. A patient, who is a potential beggar, lives in a State funded room beside the family house. This was a scheme to prevent beggars and encourage jobs in one poor block (a block = a section of an LCU). The scheme was successful but difficult to multiply.
- Sheltered workshops were set up for tailoring, carpentry, typing etc. for ex-TB patients, living in a sanatorium.
- Hindt Kusht Nivaran Singh started up a scheme, which had a WB State branch, to help cured but destitute ex-patients. It was a good scheme but they have only been able to resettle 25 families.

# VARANASI VISITS AND CONSULTATIONS

## 1 INTRODUCTION TO VARANASI VISIT

Varanasi is one of 64 districts in Uttar Pradesh State. Population is 47,98,000 (1991 survey). 28 of the 64 districts in U P State are now on MDT. 14 more will commence MDT on 10.1.94. The Varanasi district MDT programme commenced on 1.8.1985, following the obligatory population survey covering 90% of the population. A District MDT Society was started on 11.2.1992.

| | Before MDT 1985 | 1993 | % Decline/ D<br>% Increase/I |
|---|---|---|---|
| District population | 36,89,908 (in 1981) | 47,98,729 (in 1991) | |
| Prevalence rate | 6.40/1,000 | 0.42/1,000 | 93.43% D |
| N C detection rate | 0.34/1,00 | 0.02/100 | 94.11% D |
| MB rate among N C | 41.57% | 27.21% | |
| Child rate among N C | 14.83% | 9.80% | 33.78% D |
| Monolesion PB rate | 14.40% | 24.45% | |
| Relapse rate | Nil | 0.71% | |
| Deformity in N C (WHO grades 2/3) | 10.03% | 3.49% | 65.20% D |
| Voluntary reporting among N C | 2.88% | 32.57% | 91.15% I |

NC = New Case

There are now 2,027 patients on treatment, i.e. under 100 pts.for one NMS and only 20-25 per PMW. They are still getting 65-100 new patients per month.

There are 7 LCUs plus 1 urban unit totalling 8 units. The number of DDPs has been reduced as the case load has fallen. There are no temporary hospitalisation wards, reconstructive surgery facilities or rehabilitation centres. Twenty-two PHCs are functioning in the district.

Number of cases with grade 2/3 deformity:
Old cases 1,504
New cases 1,537
total of 3,041

Senior colleagues met during the visit:

Dr.P L Joshi Regional Director of H & F (Health & Family Welfare), Govt.of India, UP Region, Lucknow, was introduced on day 1.

The following senior colleagues accompanied all DDP visits and were involved in discussions regarding the work:

| | |
|---|---|
| Dr.S C Bhalla | NLEP Consultant for UP, based in Lucknow. |
| Dr.S N Singh | DLO, Varanasi |
| Dr.S P Singh | MO, Urban Leprosy Unit, Varanasi |

## 2. DESCRIPTION OF DDPs VISITED AND PATIENTS EXAMINED

### DDPs VISITED ON DAY 1

1st DDP:

In a village, by the side of the road, surrounded by a crowd of men onlookers. Bed available to sit on. PMW arrived late but seemed serious. He is responsible for 8 DPPs, taking 2 per week. Has a motorbike. Records were in good order but Clofazamine was missing for two 3-month periods and one 1-month period 1991-Dec.1993. Rifampacine was missing for one month.

Eight patients were listed, of whom four were seen. Of the others:

- 1 has defaulted to take local medicine after attending 10 times. Had insensitive feet. It was not clear why he had lost confidence in treatment after so many attandances. The PMW was encouraged to find out why.
- 1 is now taking medicine at a leprosy hospital nearer to his home and thus should have been officially transferred.

Pt.1: - On rx. 4 months. Large clear body patches. Pt.says that these are fading and regaining sensation. MB.
- Smear was taken 4 months ago but no result as yet.
- Sole sensation was tested with patient lying on the bed, eyes closed, touched by a feather and saying "yes" occasionally when his sole or leg had been stroked more than once. Not satisfactory for follow-up purposes.
- Two strength tests: One = finger flexion (not OK).
Second = pinch (OK).

Neither strength nor sensation records are repeated routinely.

Pt.2
and 3: Neither with completely clear diagnoses.

Pt.4: Came for surveillance check.

Only one female patient was listed to attend and her medicine was collected by her brother. No record is made when proxies take the treatment. Impossible situation for a lady to be examined in, so they say that they examine ladies at home.

Of the 8 patients' cards only the defaulter had disability = bilateral sole and dorsum sensory loss, grade 1. The PMW has seen him only once since he defaulted some months back.

2nd DDP:

In the store room of a cooperative.

Pt.1: Originally had 5 bilateral patches but was classified as PB. Completed 6/12 treatment but relapsed 2 years later. Now regular on MB treatment.
Pt.2: MB pt.who missed 7/19 Clofazamine doses (including those due 10-12.93) and 1/19 Rifampacine doses.

Pts.
3 & 4: (from Cards) Both were extending their MDT course (for 3 and 5 months to date) to cover the period in which one or other of the MDT medicines was missing.

3rd DPP:

At a voluntary organisation health centre (R.C./Buddhist). Not their DDP day so just saw the cards and a disability register.

- Checked the cards for disability and found only 4 MB grade 1s. Grade 2s are listed in their disability book.
- Problem of finding female patients. 0/8 MB patients are female and only 1/3 PBs. Difficulty of examining them.

## DDPs VISITED ON DAY 2, VARANASI

### 1st DDP/day 2 Varanasi

It is held in a rented room at a NGO homeopathic hospital. Six patients are registered for treatment. We saw 4 of them. Proxies came to collect medicine for the other 2.

- 1st patient, MB. Has had 27 MDT doses rather than the usual 24. The extras are so that he can have the required 3 skin smears taken before RFT (release from treatment).All 3 smears are negative. Clofazamine was not available on 15 occasions, Rifampacine on 1 occasion. According to NLEP guidelines, MB patients should be given only Dapsone if either of the other 3 drugs is unavailable. Thus in theory this patient should be asked to attend for a further 12-15 months before RFT. The PMW says that if his supply is short he gives it to the new cases.

  The PMW tested sensation on the dorsum of the foot, using a feather to stroke the skin.

  On reminder he tested also the sole, but only the big toe and MH5. He used pinprick and asked the patient to say "yes" when he felt the pin. The patient sometimes did and sometimes did not say "yes", despite which sensation was presumed to be normal.

- 2nd patient, an old man having a right ulnar paralysis and sole sensory loss plus a big toe burn. Both patients and staff are caring for the burn. The patient is unable to demonstrate hand exercise.

- 3rd patient, female, MB. She received no Clofazamin on 10/19 monthly attendances and missed Rifampacin on 1 occasion. She is recorded as having no disability but in fact has a complete right ulnar paralysis with clawing and a little finger scar. The paralysis has been present for 2-3 years following a tingling sensation, but was not noticed by staff and not reported by the patient (although noticed).

- 4th patient, male. Has an complete ulnar-median paralysis, the median since 1993. The PMW noticed some median wasting and Prednisolone was prescribed:
  - On 11.8.93. was given 45 X 5 mg.tablets and advised to take 6 tablets/30 mg.per day,in divided doses for 7 days, then 4 tablets per day for 7 days, then 2 tablets per day for 7 days, and then to stop. This regime called for 84 tablets. Staff had no more than 45 tablets at the time and the patient was advised to buy the extra.
  - On 11.12 93. the patient was given another 45 tablets.

The deformity register at this DDP listed 37 patients with grades 2 or above of whom 3 were graded as 4, 5 were graded as 3 and 29 were graded as 2. 7 were recorded as having died.

## 2nd DDP/day 2 Varanasi

It is held at a PHC. 16 patients should attend. 3 have already gone. 8 are waiting when we arrive of whom 2 are female.

- 1st patient. The body chart shows nodules all over the body, including the ears, despite which the smears are all recorded as negative = unlikely.
  (See comments on microscopes/smears problems).

- 2nd patient. Also has very many patches but negative smears. Possibly correct but need checking view of 1st patient.

- 3rd patient. An MB case who has reacted to Clofazamine.

- 4th patient has a right sole wound and neglected callus problem. Staff advise "soak, rub, oil" and the patient said that he is doing this but not effectively. Rubbing of such thick callus would open cracks. Staff need to visit the patient's nearby house and use a scalpel to pare skin and gradually work to improve skin and wound. Talking is not enough.

- A young lady, cured PB case, looking very worried, comes to ask if she is getting a new patch. False alarm. However, there is discussion as to the importance of the PMW checking with her and her parents in private, couselling her to believe in cure and checking in case she is having marriage-prospects problems.

## Day 3, Patients examined outside the district leprosy office.

Three male patients were called to show and discuss the plastic footwear given by the Bombay leprosy programme:

- Two walked little, the third was a petty trader and walked a good deal.
- The petty trader had recently sustained a dorsal wound from an upper edge, and this was uncovered and being irritated by the shoe. (Note. Staff were advised to heat and loosen the offending edge).
- All liked the footwear, preferring the enclosed type owned by one to the sandals owned by the other two.
- However the sandal uppers were definitely stronger than the shoe upper. The upper of the shoe split vertically for the whole heel height after 9-10/12, but was successfully and safely patched by a local shoemender. There is now a short upper split at an edge near to the shoelaces.

- 3 different types of insole cushioning material, 1 cm thick, were being used: The blue coloured insole in the petty trader's sandals has shaped a good deal and is almost worn through and with no plan for replacement. The black insole in one pair is not worn at all, and the brown insole only slightly worn.

Other former patients examined did not have the Bombay shoes but were given a pair to thank them for attending.

- Pt.4, male, has right hand ulnar/median paralysis and has undergone reconstructive surgery (lumbrical and thumb CMC opponens/flexor replacement + arthrodesis of a previously flexed IP joint). His work is to weave sari material and he reckons that the deformity has reduced his working speed by 50% although the surgery did improve function.

- Pt.5, male, was a washerman who worked in hot water and ironed clothes using a charcoal iron. He registered for treatment in 1985 at which time he had all of his fingers. Now his fingers and thumbs are shortened on both hands.
  He has longterm, smelly wounds under right MH1 and left MH3

- Pt.6, male, has a right dropped foot with shortening of his toes and 2 forefoot ulcers. No other disability. No-one has suggested either surgery (would have to be in another State) or a dropfoot support for his foot. His wife works.

- Pt.7, female, has an ulnar paralysis and some sole sensory loss but is not worried by either and has no wounds.

- Pt.8, male, came today because he heard of interest in disability problems. He reports developing both right sole sensory loss and bilateral ulnar weakness 3-4 months ago having stopped MP MDT 8-9 months ago. He has recently had hepatatis, for which he was treated by the MO at the general hospital. The hepatitis is now OK and the DLO prescribes Prednisolone from today.

- Pt.9, has bilateral ulnar paralyses but is not worried by these and has no wounds.

### 3rd DDP/day 3 Varanasi

This DDP is held outside the LCU office, where patient forms are stored, and which itself is beside a PHC. 6 patients are listed for treatment of whom 2 have already collected medicine.

The other 4 are not there when we visit. Thus we look at the deformity register, see the boy named Udaipur, and then move on. The deformity register lists 19 patients, but after 1985 only one each has been added in 1986, 1990 and 1993.

A 4 year-old boy named Udaipur, affected by cerebral palsy, was brought to see us. Can walk with help, though has a wheelchair. Might be able to cope standing with a frame. Has trouble with eating. Might be helped by WHO CBR leaflet.

## 3. DRUG SUPPLY

The supply to patients of Clofazamine has been seriously interrupted on several occasions during the past few years and the supply of Rifampacine occasionally interrupted. For example, patients cards show that Clofazamine was unavailable for periods totalling seven months during 1991-1993. Some MB patients have taken treatment on 15 occasions that lacked Clofazamine, which was evidently out of stock at district level. Many patients missed Rifampacine for one month due to a local management problem.

The DLO reports that Clofazamine is supplied by only 2 firms in India and that some delays have been due to a court case involving a firm and the MOPH.

The supply system, is as follows. Delhi places orders for MDT drugs for all States. Stocks are held in regional medical depots, for example in Bombay, Calcutta, Madras and Hyderabad and the Punjab. There is a district drug purchase committee which empowers the DLO to apply to buy drugs, usually from the Punjab regional depot. If they lack supplies the DLO can apply to other depots to see if they have stocks, e.g. Hyderabad. However sometimes Clofazamine is unavailable.
According to the NLEP Consultant, MB patients should in theory receive Dapsone alone when either Rifampacin or Clofazamine are unavailable, and should then lengthen their course of treatment so that they received 24 doses of MDT. However these guidelines were evidently not being followed. Were they followed, some MB patients would need to continue on treatment for more than one year longer than necessary, implying much inconvenience.

| MDT drug stocks as of 31.12.93. | In stock | Expiry date | Needed per month now |
|---|---|---|---|
| Rifampacin 300mg | 11,000 | 8/94 | 5,000 |
| Clofazamine | Nil* | - | 48,000 |
| Dapsone 100 mg | 80,000 | 9/94 | 60,000 |
| 50 mg | 5,000 | 7/94 | |

*The DLO reports receiving new stocks of Clofazamine on 8th January 1994, but even then received only 50,000 tablets which is enough for only one month supply to patients.

DLO's written comments regarding coping with drug shortage:

"If shortage is general in the district then nothing can be done. If it is local then he manages from other units". He does have good storage facilities and would like always to have 3/12 of stocks in hand.

In theory, fixed duration therapy is practiced in the district, though with 14 days intensive phase for MB patients. In practice, MB patients continue for several extra months while 3 consecutive smears are taken to check that they are negative. Other patients continue for longer because they had missed Clofazamine when taking treatment during some months.

Monolesion patients are managed through early detection and regular treatment.

## 4. SMEARS/MICROSCOPES

An unlikely smear reading was observed at the 2nd DDP visited on day 2 Varanasi. A patient whose body chart showed lesions over most of the body, and including the ear lobes, had a negative smear result on diagnosis. A second patient had very many patches but negative smears. This was possibly correct but needs checking view of the first patient.

Comments by the DLO in regard to smear-reading and microscopes:

- 100-150 slides are taken per month.

- 17 microscopes are available. 10 are working, but only 3 of these are functioning reliably = 1 in the DLO office and 2 in LCUs. The other 14 are unreliable, some having been had problems with the oil immersion lenses since purchased.
  5 were from the State HQ. 9 were purchased by the previous DLO. One (or more) sent to Lucknow for repair over 1 year ago have not yet been returned.

- However any queried slides can be brought to the DLO's office to be read.

- The DLO reports some slackness in the laboratory technicians.

## 5. FUNDS MANAGEMENT

For some reason, many of the SIDA funds have not reached the district. The pending liability is 15,22,000 rp up to 31.12.93. In theory, both MOs and NMSs should visit 100% of their unit DDPs each month. However lack of incentives funds for 3 years makes this impossible at present. The DLO is concerned lest funds are even less when SIDA funding stops.

### 5.1 Sources of funding

a) The MOPH originally gave funds for an expanding leprosy service for 5 years, 1985-90. Now ceased.

b) Funds from the Central Govt. coffers (not MOPH) come direct to the DLO office.
- These cover salaries of 235 staff,
- TAs and DAs (Dearness Allowance for rising prices)
- POL and maintenance for 8 vehicles,
- contingency funds (e.g. office rent, electricity, stationary)

c) Funds from SIDA via WHO (there are no other funds coming through WHO) to the DLO who is the secretary of the Society in whose account the funds are deposited. The District Magistrate is the Chairman of the Society. These funds are theoretically to cover:

- Staff incentives (admissable at the start of MDT, but due to cease in Varanasi District from 31.12.93) as follows p.m.:

DLO 500RP
Other MO 400RP
NMS 300RP + 30RP cycle allowance,
PMW 200RP + 30RP cycle allowance (no extras for using own motorbikes)
Statistical Asst. 250RP
Driver and physio.tech each 200RP , etc.

### 5.2 Funding for vehicle maintenance

- The State Government gives 7-8,000 RP p.a. for POL and maintenance.
- WHO/SIDA give 15,000 RP p.a. for maintenance of SIDA vehicles, plus 1,000RP extra for each State vehicle.

### 5.3 TAs (Travel Allowances)

Staff get TAs (Travel Allowances) when they travel beyond 8 km, i.e MOs and NMSs receive TAs and PMWs only if asked to cover for a neighbouring area. Travel costs have gone up 10-fold but the TA levels have stayed the same.

The district currently receive 50,000RP p.a. for TAs for 235 staff which averages roughly at 200RP p.a. per staff member.
200RP would be enough:

- for 2 trips from Varanasi to the State HQ in Lucknow, or
- for 4 trips to a distant PHC within Varanasi district.

Thus the district currently spends about four times the 50,000 RP allotted for TAs ... the extra being out of staff pockets. Thus there is much liability pending. Staff put in claims and receive a proportion of what was spent in the new budget year.

The work suffers due to paucity of TA. An NMS travels to supervise 4-5 PMWs He needs 5,000RP p.a. to cover a circuit of around 35-34km. There are 26 NMSs in total in 8 LCUs.

In theory both MOs and NMSs should visit 100% of their unit DDPs each month. Lack of incentives funds for 3 years makes this impossible at present. However, in practice they do manage to visit at least 50%.

Some also receive city top-up and housing allowances.

As there are still *65-70 new cases per month, the DLO recommends that the incentives are given for one more year (they stopped at end of 1993).*

## 6. HEALTH EDUCATION

There has been interaction with community leaders 18 times during the past 6 months. According to the DLO, these leaders react favourably to these contacts and cooperate with leprosy staff. The main method of health education seems to be through informal discussion with community members who ask questions and patient contact. Some leprosy posters were seen at the LCU office. DDPs were not inside PHC centres.

### 6.1 Means of assessing the impact of health education are:

- increase in voluntary reporting by 91.15% since 1985,
- decrease in the new case detection rate by 33.78% since 1985,
- significant lessening of stigma as reported by staff comparing attitudes of community to patients between 1985 and now.

## 7. STAFF AND THEIR TRAINING

Prior to the introduction of MDT three MDT orientation courses were held, two 3-day courses during 1984 plus a 3-month operational training course from 30th January to 30th April 1985.

Staff levels and training status on 31.12.93. were as follows:

| | Sanctioned | Available | Trained | Not trained |
|---|---|---|---|---|
| District Leprosy Officer | 1 | 1 | MDT | - |
| Medical Officers ........ | 9 | 8 | 2 | 6 |
| Non Medical Supervisors . | 26 | 26 | 26 | - |
| Para Medical Workers .... | 135 | 132 | 132 | - |
| Laboratory Technicians .. | 16 | 16 | 16 | - |
| Physiotherapy Technicians | 2 | 2 | 2 | - |
| Health Educators ........ | 2 | 1 | 1 | - |
| Drivers ................. | 8 | 8 | 8 | - |
| Administrative staff .... | 10 | 10 | - | - |

Medical Officers plus NMSs plus PMWs total 166, treating 2,000 patients currently on MDT.

### 7.1 DLO

Dr. S N Singh has been working in leprosy, and in this district, for 2 years. He underwent a 2-week leprosy (MDT) training course at Jalma, Agra, in Setember 1993. Dr.Singh considers that it will be possible to eliminate leprosy from the district in the coming few years.

Important operational and administrative problems are:

- periodic interruptions in drug supply,
- non-arrival of SIDA funds,
- that rehabilitation activities, surgery and physiotherapy are not provided, and
- that the DLO needs more power to work independently.

### 7.2 Leprosy Medical Officers (MOs)

There are currently 8 MOs + 1 vacancy + 1 MO away for a year for special training. Thus currently one MO is covering the hospital and an LCU, a second is covering two areas. Only 2 of the 8 have undertaken the basic leprosy training course. MOs who don't want to work in leprosy refuse training because, once trained, they will have to stay in leprosy work for some time. There is a stigma attached to staff working in leprosy and MOs get narrow experience. One of the current MOs (who has asked for a transfer) is a dermatologist. The DLO said that in future MOs who refuse training opportunities are to lose their 400RP per month incentive allowance.

One of the MOs, Dr.Singh, is looking after both his own urban area and one other LCU.

### 7.3 Leprosy staff are less busy than before, due to the declining prevalence

However the DLO says that the workers are being kept busy because:

- every MO should visit his field units for 18-20 days per month,
- every NMS should visit his field units for 25 days per month,
- every PMW should be doing some work each day except for holidays, for example: manning DDPs on pulse days, visiting contacts, tracing defaulters, counselling patients, carrying out surveys in school, slum and industrial areas or undertaking health education activities designed to interrupt the chain of infection.

Due to lack of funds and TAs and vehicle problems in practice MOs and NMSs are not able to keep to this schedule, though do visit for at least 50% of these periods.

**1 NMS** serves a population of 1-1.5 lakhs (1 lakh = 1,000,000).
**1 PMW** serves a population of 25-30,000.

### 7.4 Physiotherapy technicians

There are currently 2 physiotherapy technicians employed in the district, one trained at Purulia and one at Chingleput. One works in a leprosy hospital and one in the field, travelling with the MO sometimes and training individual patients. There are 2 Physiotherapy Technician posts for each of 4 units.

### 7.5 Comments by an NMS

He has been an NMS for 9 years. He is happy with his work on the whole except for:

- TA (transport allowance) problems, and
- periodic lack of drugs.

He should tour for 20 days per month, but during the past 3 months has only managed 8-10 visits per month due to lack of TA. His pay has risen from 650 rp salary + 300 rp incentive per month to 2,200 rp salary + 300 rp incentive per month. However " the cost of living has multiplied 10 times, and the cost of petrol has risen from 8 rp to 20 rp per litre.

He reckons that about 5-6% of patients default, but this data is not collected at district level.

### 7.6 PHC staffing

There is one Primary Health Centre (PHC) for every 1 lakh population.
PHC staff consists of:

- 2 Medical Officers (MOs),
- 1 Health Educator,
- 1 Pharmacist (who prepares/distributes medicines),
- 1 Laboratory Technician
- 4-6 Senior Grades Multi-Purpose Workers (MPWs)
- 1 Health Visitor who travels round supervising the EPI and coping with home deliveries and mother and child health (MCH)
- 10-12 MPWs, some male and some female, whose work includes visits to villages.

**Each PHC has 8 subcentres** staffed by two multipurpose workers, one male and one female.

## 8. SURVEYS

The weakest point of the programme is surveying, especially amongst females (Dr.Bhalla).

There are 1,777 primary schools and around 476 middle schools in the district. 1993 surveys in 6 primary schools brought about 17 new cases to light. 1993 contact surveys, focussing on MB cases, bring many new patients to light, for example out of 86 new cases identified during December 1993, 36 were found through contact surveys. Voluntary reporting is unevenly distributed and not always around 90%.

## 9. VEHICLES

There are 8 State vehicles and 3 Society/SIDA vehicles of which only 5 are on the road. Two of these need minor repairs.

The system for getting funds for repairs costing over 2,000RP is cumbersome. Requests have to pass from the DLO to Dr.Mittal to the WHO Regional Office (in same building as Dr.Mittal) to WHO main office (in separate building) to be sanctioned, and then back to the DLO.

## 10 DEFORMITY DATA

### 10.1 WHO grade 2/3 deformity

Old cases 1,504
New cases 1,537
Total of 3,041
There is no breakdown of this data by sex or into eye,hand and foot grading.

No district data is available as to numbers with specific impairments such as lagophthalmus, claw hands, dropfoot and plantar ulcers but some such information could be obtained from the body charts completed at registration on individual patient cards. Hand and foot sensation records are unreliable. For example, at the first DDP visited, only one of the 8 patients' cards, that of the defaulter, showed a disability problem -- sensory loss of both aspects of both feet, grade 1.

### 10.2 Surgery

No list is kept of patients requiring surgery because surgery is not available. One patient was seen who might have benefitted from lagophthalmus correction surgery and one who needs dropfoot correction surgery, and meanwhile needs a dropfoot support. (Note. W.H.O.instructions as to how to make a support have been sent to the DLO, and Purulia hospital has been asked to send to him a sample that could be copied).

### 10.3 Deformity registers

These were available in Varanasi District, one for each PMW's area. Thus there are 4 registers per each PHC area. However all registers examined were out of date, most containing few or no entries after 1985. One, written in English, listed an exceptionally high number of 78 patients, being for an industrial area to which many people have migrated. Most of those listed had registered for treatment by 1985, with the latest 2 registered in the English-language register in 1989. As the register covered a number of years and was out of date, it was not possible express the disabled as a percentage of patients examined. A second register written in 1985 for a similar size of area listed only 17 disabled patients.

Breakdown of disability data in the 62 patients who were not recorded as having died or left the area showed the following:

EYES - 1 patient had lagophthalmus.

HAND - disability had been recorded as affecting 53 patients:
- 11 with 1 finger clawing,
- 14 with 2 finger clawing,
- 3 (aged 20, 40 and 50) with 3 finger clawing,

- 2 (aged 32 and 50 years) with 4 finger clawing,
- 1 (aged 30 years) with 5 finger clawing.
- 12 have unspecified "hand deformity", 3 bilaterally
- 1 hand is recorded as operated on in Madras
- 4 are recorded as having only "loss of muscle".

FOOT - disability had been recorded as affecting only 13 cases:

- 2 with footdrop (1 case bilaterally)
- 4 with foot ulcers recorded
- 3 with feet deformed (2 bilaterally), and 3 with toes deformed
- a total of 12 have evidence (including the above)of foot sensory loss.

SENSORY LOSS ONLY

- 16 are recorded as having loss of sensation only, not always being specified whether this affects hands and/or feet.

AGES - 18 (2 cases), 20-29 (9), 30-39 (16), 40-49 (17), 50-59 (14), 60-69 (4), 70+ (4)

### 10.4 Comments on the disability data

- 27 of the disabled patients listed were under 40 years of age at diagnosis around 1985, a further 17 aged 40-49. Most of these will still be working and it is important that they be reviewed to check if and how their disability and dehabilitation have increased and what help, if any, they now need.

- It is important to find out how much of the hand deformity inconveniences patients in some way ... and if so, how it affects them. More than 50% of the 53 people with hand deformity have only 1 or 2 finger clawing or loss of muscle, which may not trouble them.

- Foot sensation is poorly tested as evidenced not only by observation during DDP visits but also by the low %s registered with sole sensory loss as compared with hand problems. Staff and the NLEP Consultant comment that the hand is easier to check than the foot, especially at DDPs where patients are usually standing. However if foot ulcers and deformity develop over the years in an insensitive sole, they can cause great inconvenience.

- The male female ratio was given as 51:14, which seems unlikely.

- 7 of those graded as 1 are recorded as having hand deformity and 2 as having loss of muscle. The former, and probably the latter, should have been graded as 2.

## 11. DISABILITY CONTROL ACTIVITIES

### 11.1 SNF

Pt.8, male, came today because he heard of interest in disability problems. He reports developing both right sole sensory loss and bilateral ulnar weakness 3-4 months ago, having stopped MP MDT 8-9 months ago. He has recently had hepatitis, for which he was treated by the MO at the general hospital. The hepatitis is now OK and the DLO prescribes Prednisolone from today.

### 11.2 Self-care training

DLO: Some health education is given to all patients to prevent deformity, and to those having deformity to teach the patient how to care so that it may not worsen.

Pt.5, male, was a washerman who worked in hot water and ironed clothes using a charcoal iron. He registered for treatment in 1985 at which time he had all of his fingers. Now his fingers and thumbs are shortened on both hands. He has long term, smelly wounds under right MH1 and left MH3

### 11.3 Provision of protective devices

- 400 pairs of plastic, MCR footwear incorporating steel, sole shanks were gifted to the district one year ago from Dr.Antia and colleagues in the Bombay Leprosy Programme. 386 pairs have been distributed, to 257 MB cases plus 129 PB cases. However the district has no funds to replace them.

- Pts 5 and 6 need protective footwear.

- Pt.6, male, has a right dropped foot with shortening of his toes and 2 forefoot ulcers. No other disability. In the absence of surgery, he needs a dropfoot support.

### 11.4 Ulcer care

- Pts 5 and 6 need wound attention

### 11.5 Identifying presence/absence of dehabilitating influences and taking action to minimize dehabilitation where identifed

- Could the working speed of Pt.4 be improved by aids?

- Pt.7, female, has an ulnar paralysis and some sole sensory loss but is not worried by either and has no wounds.

- Pt.9, has bilateral ulnar paralyses but is not worried by these and has no wounds.

## 11.6 Reconstructive surgery

- Pt.4, male, has right hand ulnar/median paralysis and has undergone reconstructive surgery (lumbrical and thumb CMC opponens/flexor replacement + arthrodesis of a previously flexed IP joint). His work is to weave sari material and he reckons that the deformity has reduced his working speed by 50% although the surgery did improve function.

## 11.7 Monitoring effects of action to control disability and dehabilitation

No monitoring is taking place, nor do records include any relevant measurement indicators.

# DAY-LONG VISIT TO BANKURA DISTRICT

## 1. JANUARY 7TH/DAY 4 - TRAVEL TO BANKURA DISTRICT

Population density is 370 people per sq.km.in WB.

The Bankura DLO Dr.Biswas has spent 3 years in leprosy work. Before that he took a public health diploma course and spent 10 years as a district family welfare officer.

Visit Gouripur Regional Training and Research Institute (RTRI) of the Central Government and State Government Leprosy Hospital which are in the same compound. In addition, see some of the 50 hospital beds that are used for patients as a demonstration facility. An epidemiology department was established here one month ago.

Meet the Director Dr L S Chauhan and the Assistant CMO for Bankura District, Dr.A C Mandar, who was surgeon at thie hospital for 10 years.

Discuss available Training Centres

a) The Regional Training and Research Institute at Gouripur, run by the Central Government offers training courses for laboratory technicians, PMWs and NMS. They are now, for the first time, offering an MO course. There were no applicants for the first suggested course, but some are expected for a course scheduled to commence in April 1994.

b) The State Government runs training courses at Bankura.

c) TLM Bankura Leprosy Home and Hospital has field unit and in-patient beds and conducts courses for laboratory staff.

d) The TLM Hospital in Purulia runs courses for leprosy physiotherapy technicians.

e) 3 year courses for physiotherapists are conducted in Medical Colleges and Post Graduate Institutes. However these are not presently taking new candidates because those qualified are not yet absorbed, some being without jobs. Physiotherapists are employed mainly in district and state hospitals.

The RTRI *serves the Eastern States of Bihar and West Bengal plus the 4* North Eastern States. Courses held during 1993 were as follows:

- 6 NMW courses, each for 10 trainees,
- 18 PMW courses, each for 10 trainees.

In future most States will conduct their own PMW courses. However the RTRI will also conduct PMW courses where there is demand. For example in 1995 they will train PMWs for Kashmir. A new MOs course is on offer. There were no applicants for the first course, but some are expected for the next scheduled course due April 1994.

A one-day course for private practitioners in the area may be considered. Some patients take private treatment. Although some of the private doctors have leprosy knowledge (e.g. 2 dermatologists in Bankura), others don't. 25 patients sent to the RTRI for skin smears from knowledgable doctors were all on MDT, though not necessarily the WHO-recommended course.

### 1.1 Discussion with RTLI doctors regarding disability control activities

a) Recommendation regarding Prednisolone treatment:
Doctors in the RTLI office said that they usually do <u>not</u> give Prednisolone for type 1 reaction. They may give it for type 2 reaction, particularly for nerve pain.
A course of treatment is usually 45 days to 3 months. Dr.K C Das said that he has the impression that more patients suffer type 1 reaction on MDT than on monotherapy, though he has no data to support this observation.

b) A physiotherapy record is made by the physiotherapy technician for patients with grade 2 or 3 disability, but not for grade 1. The current physiotherapy technician was trained at the TLM Hospital in Purulia, but was on leave on the day of the visit.

c) The MOs and nurses give some education regarding wound avoidance and care.

### 1.2 Visit Gouripur State Govt.Leprosy Hospital which is on the same compound

This is the main Government facility for in-patient treatment for the whole state, having 500 beds and daily out-patient services. Referrals are accepted from the whole State. Some come on their own. It is an old hospital from pre-Independence time. Dr.C K Das was at one time Superintendent here.

a) Visit some patients in the mostly empty wards.

b) Visit the physiotherapy department. The physiotherapist, who trained in Calcutta, has worked at this hospital for 3 1/2 years and says that he has not made a single physiotherapy record during this time, nor presumably have the MOs insisted that he do so. His work is seen as giving wax treatments, teaching exercise, making plaster casts and supervising the shoe-making workshop. Patients seen exercising did not need the exercises that they were being taught.

The physiotherapist has had no leprosy training and said that leprosy was not taught during his physiotherapy course in Calcutta. When Dr.K C Das asked if he wanted arrangements to be made for him to visit a physiotherapist at a leprosy hospital he replied "I'll think about it"!

c) Visit the Shoe-making unit. Two shoemakers made between them only 30 pairs of protective sandals during 1993. Six patients await footwear now. Problems include: lack of funds for materials. If patients pay, they take foot drawings, buy materials and make the footwear. Charges to patients are: full rate 65 rp, half rate 32 rp, or free.

Comment: The X-style being made has extra wide straps and is very wasteful of leather. Suggest they try the Y-type, obtaining patterns from TLM Purulia, via Dr.Biswas or the SLO.

### 1.3 New cases in Bankura

In 1988: 5886, 1989: 3612, 1990: 3405, 1991: 4291, 1992: 3922 and in 1993 up to end of November: 4121 (expecting by year end: approximately 4500).

In 1993 24.36% of new cases were MB as compared with 32.36% in 1988 indicating that cases are being detected earlier.

### 1.4 New case finding indicators

Bankura child cases 1993:
MB 103/1004 (10%), PB 972/3117 (31%)
= Total 26%
Deformity in NP MB 46/1004 (4.58%), PB 29/3117 (0.93%)
= Total 1.82%

Voluntary reporting percentage in Bankura had gone up since an extensive health education campaign was commenced in 1992. From 37% in both 1990 and 1991 to 42% in 1992 and 52.35% up to November in 1993.

### 1.5 Surveys

Starting 1993 staff have been organizing a stratified random survey. Findings will give a better idea of the patient load in the community. As the team moves in field, public awareness of leprosy increases.

### 1.6 Proxies

Dr. Biswas said that 2 consecutive proxies for collecting medicine on behalf of a patient are not usually allowed. However one can record "ulcer/schoolgirls ... advised proxy" in special cases. Now is harvest season and many who have been away for labouring jobs will return January 14. Staff can give advance doses for this type of situation, recording this in the patient's notes.

### 1.7 Shortage of funds for Prednisolone

Bankura estimated Prednisolone needs as 2,000rp per LCU per month since 5% of all cases need Prednisolone. Thus 100,000 to 120,000 tablets of Prednisolone are needed, costing 48,000 rp., yet the total allowance for all non-MDT drugs is only 12,000 rp. Access to Prednisolone is a particular problem since the pharmaceutical companies are unwilling to supply the Government at their fixed rate because the market rate is now higher. Because of this shortage, staff give "minimal doses", e.g. 10 mg. p.d. in the field. If patients need bigger doses, they are referred to hospitals which have a separate budget and can supply. Bankura uses the same fund to buy Vaseline (sometimes), bandages and other drugs.

Bankura has run its MDT programme for only 6 years. Therefore they get a special allowance for extra drugs. However, Purulia has not received the extra allowance since April 1991 because they have completed the 9 years during which extra allowances are permitted.

### 1.8 Health Education

- Bankura TLM have a Health Education unit which moves to the field according to a schedule. When NLEP ask for their help, TLM provides it.

- The leprosy team have met all panchayats and Integrated Child Development Schemes (Women's groups care for children up to age 6 and for females aged 14-44, or of child-bearing age for immunizing, nutrition etc. during 3-month training courses). They teach early signs of leprosy and list treatment dates for all panchayats, women's groups, health workers, MOs and some medicine shops. The groups then refer cases. At PHCs, a notice has been painted on the wall to give information on leprosy together with the advice "don't fear" and "it may not be leprosy".

- A written appeal was sent to all head teachers describing salient features of leprosy and to use slides. When films are required, they ask TLM who are very helpful.

## 1.9 Special Drives during the year

- Stratified random survey No. 931/0 to estimate the present load in the district and give indirect propodanda to the NLEP.
- Meetings with all the 19 Panchayat members:
  19 at samity level and 171 at anchal level.
- Painting notices on the health point walls x 116 at the BPHC/PHC/SHC/SC level indicating salient features on leprosy and "pulse calendar" (clinic timetable)
- Distribution of pulse calendar to all concerned.
- Distribution of MDT Q & A to all PH Centres and local practitioners.
- Meeting with all Health Staff of the 22 Blocks in the District and ICDS staff with slide projector.
- Meeting with PHC Indoor Nursing Staff and Teachers of the GNN Training School of BSMC&H, Bankura.

Since Sept.1993 they have been meeting at village level with the Panchayat Members, Clubs, Voluntary Organisations, teachers etc. asking help and active participation during the proposed stratified random survey which started in November '93. All reports are expected to be completed in March '94. By means of all these activities voluntary case detection has been increasing gradually and is at present nearly 60%.

## 1.10 Protective footwear

Staff supply one-size-bigger canvas shoes costing about 70 rp. per pair, and put an extra hard insole inside to compensate for a very thin sole. Cracks are a big problem in winter.

## 1.11 Overview from the Bankura annual report

India estimated case load at 2.2 to 2.5 million. Spread all over India but varies from State to State, district to district and within the district itself. The areas of high prevalence are found mainly in the SE and central parts of the country including Tamil Nadu, AP, Orissa, Bihar, Uttar Pradesh, Maharasthra and WB. Between them these 8 states account for approximately 90% of the registered cases in the country. About 15-20% are children below the age of 14 and an equal number suffer from deformities.

a) Pre 1955 the NLCP (National Leprosy **Control** Program) LC activities were mainly organized by the charitable missions and NGOs in a clinic approach and IP rx. with Dapsone.
- 152 institutions with 19,600 bed-strength:
  142.6 beds/1,000 estimated cases.
- 1203 Clinics: 1 clinic/300,000 population.

b) In 1955 NLCP was launched, the last year of the 1st 5-year plan with the main objective of controlling leprosy through domiciliary rx. with Suplhone. Started as a centrally-aided scheme but ultimately converted into a centrally-sponsored program in 1969-70 with total expenditure on it being charged to the central government.

c) In 1980 the NLEP the programme was accorded a high priority and re-designated as NLEP (**Eradication** rather than **Control**). Approach was based on:
- MDT
- Education of patients, their families and community re the disease and its curability
- Physical, social and economic rehabilitation of cured patients.

Stratification of WB districts according to prevalence rate:

| | |
|---|---|
| - Less than 2/1,000 | 177 districts |
| - 2 - 4.9/1,000 | 77 " |
| - 5 or more/1,000 | 201 " |
| TOTAL | 455 districts |

In WB all the districts are in the category of high (5+) endemic area except for Calcutta and Darjeeling districts where PR is 2-4.9/1,000.

| MDT Districts in WB | MDT started in the year |
|---|---|
| Purulia | 1982 |
| Bankura | 1988 |
| Bardhaman, Birbhum & Mednipur | 1991 |

24-Paraganas (N), 24-Paraganas (S), Hoogly, ) All set for the
Nadia, Murshidabad, Malda and Jalpaiguri ) start of MDT
Dinajpur (N), Dinajpur (S), Cooch Behar, ) Ready for MDT
Calcutta and Darjeeling ) at the clinic

Staff directly involved: 8 MOs including DLO, 16 NMSs, 110 PMWs, 9 lab technicians, 1 Health Educator, 1 PT, 9 drivers, 11 clerks, 8 peons, 1 nightguard.

### 1.12 Indirectly helping the programme at district level

a) The Chairman of the Society (District Magistrate) and his office
b) Panchayat members at all levels
c) All the staff a) RLTI at Gouripur, b) Gouripur Leprosy Hospital, and c) TLM hospital
d) Family members of the patients
e) Different clubs, organistions etc.

### 1.13 Helping at State level

- SLO
- Dy.Director of Health Services and his office
- Consultant, Dr.A K Halder

<u>Their basic need for smooth running of MDT programme</u>

a) Regular flow of MDT funds and State funds
b) Regular flow of MDT drugs
c) Placement of 2 new diesel vehicles against the condemned vehicles
d) Over and above active cooperation from all corners.

## GENERAL SUMMARY

### 1. POSITIVE EFFECTS OF SIDA FUNDING

- Encouraged/enabled 1982 MDT trials in Wardha and Purulia, which were pilot projects setting a plan later copied in other districts.

- When SIDA funds to aid MDT implementation reach the district, they are much appreciated. The funds make more travel possible through provision of more vehicles and extra incentives/travel allowance, thus enabling there to be surveys, more drug distribution points and better supervision of the work. Flexibility of funds has enabled needs to be met immediately whilst due funds from Government sources take time to arrive. However many of the due SIDA funds have failed to reach Varanasi for the past 3 years. This problem has possibly been due to errors in the ways funds were applied for, but this should have been identified at an earlier stage, because their lack of funds has led to a cutback in the number of supervision visits and funds for travel allowances, POL (Petrol, oil, lubricant) and vehicle maintenance were also insufficient. Funds for travel allowances for the first three months of 1992 in Purulia, just before cessation of SIDA funding, have not arrived it seems.

### 2. GOOD NEWS:

- Reduction in annual case detection rate
- Reduction in child percent rate
- Reduction in deformity percent rate in new cases (but the reliability of deformity data is questionable)
- Lessening of stigma is shown by increased visible acceptance of patients in the community and by increased readiness of patients to be examined in public.
- Staff now have lots of time available to pay more attention to women's privacy, POD etc.
- Some motivated and experienced staff.

### 3 PROBLEMS:

#### 3.1 Unsure how many early cases are unidentified

a) The new case detection rate is higher than anticipated by the NLEP at this stage in Varanasi and is levelling out in Purulia. Why so high at this stage? How much overdiagnosis is taking place?

b) Are women being identified early? The lack of privacy at DDPs would tend to discourage women from coming forward. There is a need for maximum practical privacy, e.g. by holding up a cloth for privacy at open-air DDPs, and by using PHC rooms where available.

(The reduction, however, in new case detection between 1985 and 1993 from 12,000 to 2,000 is very commendable).

### 3.2 Defaulters are not separated from died/moved at district and state level

a) One cannot tell what percentage of those who don't die/move have completed their MDT course. It seems important to find this out. A circular has been issued, in November, 1993, to say that RFT cases, defaulters, deceased and migrated should be separated.

### 3.3 DLO staff concerns:

a) Overdue TAs and other SIDA/WHO funds at Varanasi.

b) Irregularity in supply of Clofazamine and Prednisolone (Dr.Bhalla immediately "solved" this problem by saying that Society funds can be used to purchase Prednisolone). The DLO has to send names of drugs to a purchase committee which meet only once or twice a month and sometimes not at all for 2-3 months resulting in approval delays.

c) Vacancies/lack of training at MO level in particular resulting in failure of MOs to identify illogical classifications, smear results, Prednisolone courses etc.

d) Microscope problems unsolved. 50%/50% microscope/laboratory technician problem.

e) Vehicle repairs not carrried out, mainly due to lack of funds.

### 3.4 Other problems

Prevention of disability (POD) activities are lacking, with only superficial advice on self-care being gven to patients. Patients are encountering care problems that are not being solved.

Lack of privacy, particularly for women.

Communication skills are poor, with too much one-way advice, too little listening and little or no problem-solving re POD.

Varanasi Specialist and DLO: "During the first 3 years on MDT, staff were enthusiastic and action good. However now supervision and enthusiasm are declining, partly because patients had unreal expectations, e.g. that MDT would heal wounds and reverse hand clawing.

## SOME RECOMMENDATIONS

### 1. To Enhance Bacillus Control

a) Pay overdue WHO/SIDA funds as a matter of urgency.

b) Improve consistency of supply of Clofazamine and Prednisolone. ( Note. NSL have evidently just supplied large quantities of MDT drugs to India.

c) Mend vehicles/microscopes.

d) Make supervision and encouragement of field staff and patients by MOs more systematic. Due to the fast turnover of MOs, some lack leprosy training and experience. Compile for them a list of hints regarding supervision. For example, suggest that MOs ask PMWs to bring registers and patient cards to some of the monthly unit meetings, and to:

- recheck smears of any patients whose body charts show ear nodules yet whose smears are recorded as negative,
- recheck classification of any patient classified as MB yet whose body chart shows fewer than 5 patches,
- see that the registers are orderly and ask what action staff have taken to encourage MB defaulters to attend,
- give priority to field visits to PMWs whose cards and registers suggest possible problems.

e) Stratified surveys are due to commence February 1994 in Purulia. Make sure that these take place. It would facilitate disability control planning were it feasible for disabilities, and social and functional problems arising from them and from the diagnosis, to be recorded at the same time.

f) Record male/female data at district and national levels so that it will be possible, for example, to ascertain whether females are diagnosed late or attend less regularly.

### 2. To Enhance Disability Control

a) Improve the method of recording of disabilities, incorporating measurable indicators through which the effect of action to control disabilities can be monitored in future. See recommendations in ILEP Prevention of Disability Guidelines. Add comments regarding any social and functional problem that the patient is encountering.

b) Make district disability profiles using this form and comments during surveys of present and former patients.

c) When next carrying out a stratified sample population survey for MDT purposes, list people suffering from disabilities cause both by leprosy and by other causes. Record non-leprosy disabilties on the very simple form given in the WHO Community Based Rehabilitation guidelines.

d) Repeat the disability record annually, at least in sample groups, and observe trends. For example:

- How many patients are losing nerve function prior to or on treatment?
- Observe trends in wound, open crack and bone loss prevalence as described in ILEP POD guidelines.
- Note which disabilities trigger social or functional problems for patients.
- Use this information to identify action priorities.

e) Update training (initially through use of monthly staff meetings) regarding action to control disability and dehabilitation through simple field tasks:

- Clarify "neuritis" identification and treatment regimes (minimum dosages recommended), including silent neuritis.
- Place emphasis on results and on solving problems, not just on the giving of "advice".
- Experiment with possibilities for protective footwear,including use of local shoemakers. Monitor footwear usage and durability, and wound incidence, of the 400 Varanasi patients using the Bombay (Dr.Antia) footwear distributed 1 year ago.

# SUMMARY OF MAIN COMMENTS FOR SIDA ON VISITS MADE TO PURULIA AND VARANASI DISTRICTS DURING JANUARY 1994 TO EVALUATE THE MDT PROGRAMME AND DISABILITY CONTROL ACTIVITIES

---

1. **The impact of SIDA input to the programme.**
2. **The epidemiological and public health impact of the MDT programme.**
3. **The handling of drugs and their side effects.**
4. **The utilisation of funds and cost efficiency of the programme.**
5. **The social effects of the NLEP with respect to attitudes among the public and with respect to community participation in the programme.**
6. **WHO disability index and other disability and dehabilitation data.**
7. **Lessons to be learnt from the NLEP for the future operation of the programme, in regard to action to prevent disability and social problems.**

## 1 THE IMPACT OF SIDA INPUT

SIDA input in Purulia dated from 1982-1991 and in Varanasi from 1985 to the end of December 1993. Several of the experts accompanying the visits had led the leprosy control programme at the time of the SIDA-backed MDT initiative.

1.1 All who had participated in the programmes at the time of the SIDA input greatly appreciated SIDA's role in providing both the stimulus and the funding for the initiation of the MDT programme in the districts whose activities they supported, thereby setting an example that could be followed by the Government in other districts.

1.2 The leprosy experience of the Purulia Consultants in particular was seen to be helpful to the DLO. Much has been accomplished in regard to pre-MDT discharge of cured cases and implementation of MDT with resultant significant reduction of the caseload. It was surprising that neither WHO, acting for SIDA, nor the consultants identified and solved problems of non-transfer to the district of some of the SIDA funds (see 4.1).

1.3 Dr. Mittal said that it was not planned that the standard of work should be better in SIDA-supported districts than in other districts. The Government or other agencies planned to provide similar funding in other high-prevalence districts during MDT implementation. The Bankura district programme which did not have SIDA support seemed in practice to be functioning more efficiently than the neighbouring Purulia district programme. This appeared to be due to a large extent to a combination of management experience on the part of the DLO and an almost-complete complement in Bankura of MOs trained in leprosy, whereas Purulia faced a shortage of MOs and those in situ were for the most-part untrained in leprosy.

1.4 It was disappointing, especially in view of SIDA's expectation that action would take place to prevent disability as well as to cure leprosy, to find that SIDA had not ascertained that disability prevention activities and evaluation be an essential component of the programme. Both the consultants and the DLOs lacked training and experience in the basics of action to control disability, which could have been implemented gradually as the caseload fell (see 3).

## 2 THE EPIDEMIOLOGICAL AND THE PUBLIC HEALTH IMPACT OF THE MDT PROGRAMME

In both districts visited, the numbers of new cases being identified far exceeded the numbers estimated by NLEP. For example there were 2,567 new cases in Purulia district from January to November 1993, exceeding the new patient target set of 700 new cases. It is important that realistic estimates of case loads are identified through the use of appropriate stratified sample surveys, and that results are presented by gender in order to ascertain whether female patients are being identified as early, and taking treatment as regularly, as male patients. No sample survey followed completion of the period of SIDA support in Purulia, but one is planned for 1994.

Some inaccuracies were observed in the WHO disability grading in new cases used as a new case finding indicator (see 6).

## 3 THE HANDLING OF DRUGS AND THEIR SIDE-EFFECTS

Periodic shortages of Clofazamine have presented a serious problem. Some MB patients have been given only Dapsone plus Rifampicin on 15 monthly attendances. According to Dr. Balla, the period of treatment should be extended when one of the MDT drugs is missing and Dapsone only should be given to MB patients in the absence of either Clofazamine or Rifampicin, but this is not happening in practice. Dr.Mittal has just received new stocks from ILEP.

Rifampicin was unavailable for a three-month period in Purulia.

One patient seen had a skin allergic reaction to Clofazamine.

# 4 THE UTILISATION OF FUNDS AND COST EFFICIENCY OF THE PROGRAMME

4.1 The non-transfer to the districts of some of the SIDA funds posed problems in regard to the cost of vehicle maintenance, repair and fuel and travel allowances. In Purulia there is a comparatively small shortfall of funds to cover incentives due during the first three months of 1992. In Varanasi there is a significant shortfall of 1.5 lakh rp., possibly due to mistakes in the accounting returns from Varanasi to Delhi which account for funds received but do not make clear what funds are overdue. As a result travels of MOs and NMSs were, one NMS says, cut by 50%, due mainly to non-availability of travel allowances.

4.2 According to the DLO, funding problems were being experienced by Purulia **after the withdrawal of the SIDA support there,** with shortages of funds for:

- vehicle POL (petrol,oil,lubricant) and maintenance,
- non-MDT-drugs, such as Prednisolone,
- travel allowances,
- office rent, etc.

4.3 The fall in caseload was rapid as a result of pre-MDT discharges and the shortening of the treatment period. Thus PMWs and NMSs in particular had much spare time which could have been put to better use. One PMW only had responsibility for 2 DDP days per month. In Purulia district, 91 PMWs were responsible for treatment between them for treatment of only 3,832 patients on treatment 1992-93, i.e., on average only 42 patients per PMW, 274 per NMS and 1,277 per MO. In Varanasi, where currently 2,027 patients were on treatment in November 1993, an NMS is responsible for only 100 patients on treatment, and a PMW for around 20-25. Workload of laboratory technicians is likewise meagre so that the lack of motivation mentioned by one DLO is unsurprising. This use of staff skills is not cost-effective.

4.4 Supervision is suffering in Purulia due to a fast turnover of MOs untrained in leprosy and in Varanasi due to the fact that 6 of the 8 MOs have not undertaken a leprosy training course. Some try to avoid leprosy training because they fear that they will then have to undertake leprosy work for a longer period. Many MOs dislike leprosy work because it gives narrow experience in a stigmatised field. Another factor hindering supervision in Varanasi is the non-arrival of funding for travel allowances (see 4.1).

4.5 There needs to be greater sensitivity to opportunities to increase privacy for ladies in particular, perhaps by making use of PHC rooms where available or holding up a cloth as a screen.

## 5 THE SOCIAL EFFECTS OF THE NLEP WITH RESPECT TO ATTITUDES AMONG THE PUBLIC AND COMMUNITY PARTICIPATION IN THE PROGRAMME

Signs that community attitudes have changed since 1985 in Varanasi district are:

- increase in voluntary reporting by 91.15%,
- decrease in new patient detection rate 33.78%, and
- significant lessening of stigma, at least amongst males, as reported by staff comparing community attitudes to patients between 1985 and now.

In Purulia district, percentages reporting voluntarily have fluctuated between 36% and 54% since 1987.

Health education activities in Government-run leprosy control units in Purulia and Varanasi seem low-key as compared with those in Government LCUs in Bankura district and with the Purulia district unit supervised by the Gandhi Memorial Leprosy Foundation. The latter unit centres their programme on health education, using a variety of visual aids, and have data to show that intensive community health education has proved a more cost-effective way of identifying new cases than surveys. The Bankura programme has a busy programme of health education and makes a point of systematically involving the following in leprosy activities:

- the Chairman of the Society (District Magistrate) and his office,
- Panchayat members at all levels,
- all the staff of the regional leprosy training institute and State hospital at Gouiripur and Leprosy Mission staff, including their Bankura Health Education team,
- family members of the patients,
- different clubs, women's organisations, etc.

## 6 WHO DISABILITY INDEX AND OTHER DISABILITY/DEHABILITATION DATA

6.1 For available information regarding WHO disability grading in new cases recorded since the start of the MDT programme see charts prepared by Dr. Revankar. Apart from this information there is no collated disability data in the two districts visited.

WHO deformity grading is ascertained from the body charts but several mistakes were observed during visits. For example, 4/11 MB patients at one DDP were recorded as having Grade 0 deformity, but two of the four did have disability - one each, Grade 1 and 2. Eight percent of the 73 patients on treatment at two DDPs, whose cards were examined in detail (see 6.3) had disability Grade 2, which contrasted with the 1.74% new cases reported as having deformity. A check needs to be made lest disability recording inaccuracies distort WHO disability data.

The disability grade had worsened during treatment in several patients examined, and had worsened after cure in others seen having peripheral nerve dysfunction. One patient having bilateral finger clawing had had all of his fingers at the start of MDT but all are shortened now.

The load of people having peripheral nerve dysfunction, and thus at lifelong risk of new disability, cannot be ascertained from numbers having Grade 2 at diagnosis (see 6.3 and 6.4).

6.2 Some more information as to the nature of the deformity could be collected from individual patient forms, for example, recording the presence or absence of lagophthalmus, clawing and/or dropfoot.

Sensation records of hands and feet, as checked during field visits, were not reliable. For example, in one patient staff had recorded complete loss of dorsal sensation on a hand, with no loss of palmar sensation, whereas in fact, the patient had an ulnar nerve lesion with complete sensory loss down the ulnar border of the hand and little finger (both aspects) and three finger clawing. A second patient had a dropfoot which was recorded plus an insensitive sole which was not recorded.

6.3 The nature of deformities recorded on individual patient cards of people on treatment was checked at 2 DDPs.

Of the 36 patient cards checked at the 2nd Purulia DDP visited, 12 cards (33%) showed disabilities, Graded 2 in three of the patients (8%);

- 1 showed unilateral lagophthalmos,
- 3 showed complete loss of hand sensation (2 bilaterally, 1 also showing loss of all fingers and both thumbs),
- 7 showed foot sensory loss (2 bilateral, 2 dorsal sensory loss only, 1 also had unilateral loss of toes).

Of 37 who attended for treatment at the 4th DDP during the day of the visit (not all present at the time of the visit), 7 who were examined (19%) were found to have disability. 6 of them (16%) now have WHO Grade 2 disability though only 3 (8%) were graded as 2 on diagnosis:

- Most were young and at serious risk of worsening disability,
- Two had acquired their nerve lesions whilst on treatment,
- The disability grade had worsened since diagnosis in at least 3 patients, 2 due to new nerve lesions and 1 due to a wound in an insensitive foot. Worsening in some other patients would not result in a change in grade,
- 2 required and wanted surgery, 1 for footdrop and the other for ulnar, 4-finger clawing. A third patient would have been helped by modified dropfoot

correction.

6.4 The fact that greater percentages (19% and 33%) have peripheral nerve dysfunction (Grade 1 or above) illustrates the fact that the Grade 2 data does not give a realistic idea of numbers of patients with disability and at risk of lifelong increase in impairment.

6.5 Most DDPs in Varanasi had deformity registers. However these were not up to date, most having few or no entries since 1985. None were shown during the Purulia visit.

6.6 At present no outcome data is available, basically because the disability recording system is inappropriate for the monitoring of change. Deformities are roughly shown on the initial body chart, but:

- there is insufficient sensation and strength detail and accuracy to show changes in nerve function, and
- no records are made of changes in vision, wound, cracks and bone loss status.

No measurable objectives related to disability have been set, e.g., reduce the prevalence of wounds in insensitive hands/feet.

## LESSONS TO BE LEARNED FROM THE NLEP FOR THE FUTURE OPERATION OF THE PROGRAMME

7.1 It is important that efforts are made to identify and overcome factors discouraging MO involvement in leprosy work. New initiatives and specific targets in the area of disability control might prove motivating to staff bored with routine activity, e.g., "make a disability survey/study of social needs", "act to reduce the wound prevalence".

7.2 It would also seem helpful to give inexperienced MOs training in management skills plus practical advice as to how best to check on progress when unable to visit all DDPs. For example it would be useful to ask PMWs to bring registers and patient cards to monthly meetings and then checking these for regularity of attendance and smear-taking and to see if the relationship between body charts and classification are logical.

7.3 It is important that the stratified, sample survey planned for Purulia from February 1994 takes place and that similar surveys are conducted as appropriate in Varanasi so that true estimates of patient loads are obtained periodically. Were staff to be trained in the completion of the disability record form recommended in the ILEP Prevention of Disability Guidelines, then disability information could be collected at the same time.

It is recommended that district data, particularly that relating to new case finding and disability indicators, is collated separately for males and females so that any bias can be detected, investigated and overcome if possible.

In addition it would be helpful to separate numbers of patients being discharged without completing treatment from those who have died or moved ... at present these are summarised together under a heading: "otherwise".

7.4 It is recommended that staff pay more attention to:

- Listening to patients, making sure that communication is really two-way rather than focusing on the "giving of advice". For example:
- What problems is a patient who defaults or has calloused, cracking skin encountering? (26% of Purulia patients attend irregularly).
- Is it or is it not feasible for the patient's wife to help more on the farm to allow the patient to give a wound sufficient rest to promote healing? A little help now might avoid the necessity of more help later if the wound becomes complicated. Discuss options.
- Trying to allow females patients more privacy, as far as is feasible. For example, more use might be made of empty rooms where a DDP is at a PHC centre, or of a cloth or human shield (other ladies) where the DDP is in a public place.

7.5 Action to control disability seems at present to be basically confined to general advice to patients regarding skin care and wound avoidance. It is not proving effective in most of the disabled patients seen during the visit. Much more could be done by available staff and in the DDP situation and at patients homes.

Because so much that is simple has yet to be carried out effectively at DDPs, it is recommended that priority be given to action to study disability trends, solve care-implementation problems and obtain protective footwear. More complicated rehabilitation measures could either be carried out now by hospital staff, or be delayed until the simple measures have not only been implemented but also are proving effective. Recommended reading: ILEP Prevention of Disability Guidelines for Managers of Leprosy Programmes.

7.5.1 There is urgent need for district profiles to be undertaken to clarify both the nature and extent of the impairment problem, in present and former patients, and the social and functional effects that these impairments are engendering in patients lives. A logical plan of action could be based on findings. The stratified, sample survey shortly to commence in Purulia would provide good opportunity for the gathering of such information were staff trained in completion of the disability survey form.

7.5.2 If the effects of activities on impairments and on patients' lives are to be monitored, so that problems can be readily identified and overcome, an appropriate but simple disability recording system needs to be introduced. That shown in the ILEP Prevention of Disability Guidelines is recommended, with an added question to ascertain how a) the leprosy diagnosis and b) impairments as they develop, are affecting the patient's life. Dr. Noordeen confirms that WHO disability grading is neither intended nor appropriate for this purpose.

7.5.3 If deteriorating nerve function is to be preserved, as far as is feasible, it is important that the methods of sensation testing and recording are improved, that criteria for prescription of prednisolone during silent neuritis are clarified and that all leprosy MOs have constant access to prednisolone. During the visits:

- many inaccuracies of sensation recording were observed,
- staff had been trained not to expect sensation recovery during silent neuritis and thus not to prescribe prednisolone for this condition, and
- patients had had to buy their own prednisolone where prescribed and had only bought enough for 1/12 treatment instead of the generally-accepted minimum of 3/12.

7.5.4 Self-care implementation problems and possible solutions need to be identified, and patients encouraged to adopt care habits that prove effective. Simple advice to people with nerve lesions was in a few cases seen to be effective. Two ladies seen had learnt to avoid injury. However in many cases it is <u>not</u> proving effective, for example skin was observed that was not supple despite the patient's protestations of care, new wounds had incurred and old one failed to heal. In such cases staff need to learn to investigate further and to supervise as patients practice care routines so that they may identify and overcome care-implementation problems as far as is feasible. During the visit it was very sad to see evidence of increasing disability in a number of present and former patients, many of them young. For example, a child with an ulnar nerve lesion has already injured his little finger twice. A young woman with an insensitive sole has a wound that has become recurrent since first incurred only 7 months before. All fingers are now shortened in the hands of a laundryman who started treatment with clawing but having all of his fingers and thumbs intact.

7.5.5 Plans regarding protective footwear need to be made, implemented and monitored in regard to effectiveness, access, durability and acceptability. There is currently no system for systematic provision of protective footwear in either district or for advice to patients as to what footwear to buy when special footwear cannot be provided:

- In Purulia the DLO needs to liaise with the Leprosy Mission hospital superintendent in order to clarify when protective footwear can be provided to patients lacking funds to buy.

- The Bombay programme gifted 400 pairs of plastic protective footwear to Varanasi 1 year ago. The effect and durability of this footwear needs to be evaluated in Varanasi and Bombay approached to see if they are planning to donate footwear on an ongoing basis. 3 patients were seen wearing the footwear. In one case a sandal had caused a wound. One shoe had split seriously but been successfully mended locally. These patients were pleased with the footwear and it was proving durable.
- The most protective footwear available through local shops and local shoemakers, in different price ranges, needs to be identified and publicised for patients with insensitive soles.

7.5.6 Action to minimise social dehabilitation. It was good to see the Purulia Consultant, Dr. K. C. Das, go to visit the home of young, highly infectious MB patient and to ascertain his home situation and the community's social problems. His wife and daughter had left him to move to the house of his brother's family, on the same compound.

A young lady of marriageable age, cured of PB leprosy, came to one DDP to check anxiously whether or not she was getting a new leprosy patch. Staff now plan to visit her and her parents at home to check whether or not they have anxieties and if the diagnosis is resulting in any social or marriage problems.

Simple action to overcome anxieties at an early stage of dehabilitation can often prevent serious rejection problems and needs to become a routine part of care ... staff learning to routinely enquire if and how leprosy is affecting patients lives and if they can be of help in solving problems.

7.5.7 Reconstructive surgery. In Purulia a misunderstanding existed regarding costs of surgery at the Leprosy Mission Hospital. Thus two of the three patients seen who would benefit from surgery were referred to the TATA hospital, to await the next visit of Dr. Srinivasan, rather than to the Purulia hospital. No surgery service is currently available at Varanasi. Such a service is obviously highly desirable, though simple measures outlined above would seem to be the first priority.

7.5.8 Loans available from banks to buy work tools, a petty trading stand, a buffalo and the like as appropriate for jobless patients, have not as yet been applied for as by some voluntary agencies. According to Dr. Das, Social Workers might be able to become involved in investigating use of these resources were they to learn from the experience of other leprosy projects already doing so.