



**Beneficiaries of AIFO Supported Projects in 2004**



## Introduction

This report presents a synthesis of persons benefiting from different services offered globally by AIFO supported projects in the world. This report is based on the information collected from different projects for the year 2004.

These numbers can give only a partial idea of impact of the projects supported by AIFO. For each of the significant projects supported by AIFO, there are more detailed specific project reports and sometimes, independent evaluation reports that can be consulted for more information.

The date presented in this report is approximate because of several factors, such as:

- Some beneficiaries may be counted more than once as they may be benefiting from different services of the project. For example, some leprosy affected persons may receive specific anti-leprosy treatment, may also benefit from activities of socio-economic rehabilitation.
- Some beneficiaries may not be counted. For example, for activities like repairs of houses, one beneficiary is calculated while in reality, the actual number of persons benefiting from this activity may be much more.
- Beneficiaries of some activities such as health education are difficult to count.
- At the time of preparing this report, information from some projects or some of their activities was not received.

The major activities supported by AIFO through the projects include diagnosis and treatment of leprosy patients, prevention of disabilities, medical rehabilitation and socioeconomic rehabilitation activities related to leprosy affected persons, primary health care activities, community based rehabilitation activities, community development and activities related to vulnerable children.

The fight against leprosy, prevention of disabilities due to leprosy and medical and socioeconomic rehabilitation of persons affected with leprosy is the centre of AIFO's work. Over the past decade, AIFO has been promoting integration of all leprosy related activities in primary health care and community-based rehabilitation, specifically by promoting human rights and community based participatory approaches in which communities and local organizations play a key role.



A training course on prevention of disabilities among leprosy affected persons in Mozambique

## Beneficiaries of Different Kinds of Interventions Supported by AIFO

Globally, through the project supported by AIFO during 2004, a total of 273,683 persons were benefited in the following manner:

- **New Cases of Leprosy:** 40,298 new cases of leprosy were diagnosed in AIFO supported projects during the year. All these persons were treated with MDT.
- **Other Medical Care Activities related to leprosy:** Other leprosy affected persons benefiting from medical care activities of these projects including ex-patients and persons having complications due to leprosy, were 43,291 persons.
- **Socio-economic Rehabilitation Activities:** These activities are directed at leprosy affected persons, their family members and other poor and marginalised groups in the community. During 2004, beneficiaries of these activities were 10,106 persons.
- **CBR** – Activities of community-based rehabilitation (CBR) reached 47,751 persons including home visits, provision of orthopaedic appliances, support for self-help groups, etc.
- **Primary Health Care activities:** PHC activities benefited 113,778 persons during 2004.
- **Vulnerable Children:** Finally, AIFO supported projects helped 18,458 children in situations of poverty, leprosy, disability and marginalisation.



A Community meeting at Bhaki: This project conducts activities for diagnosis & treatment of leprosy, socio-economic rehabilitation, community based rehabilitation & support for vulnerable children

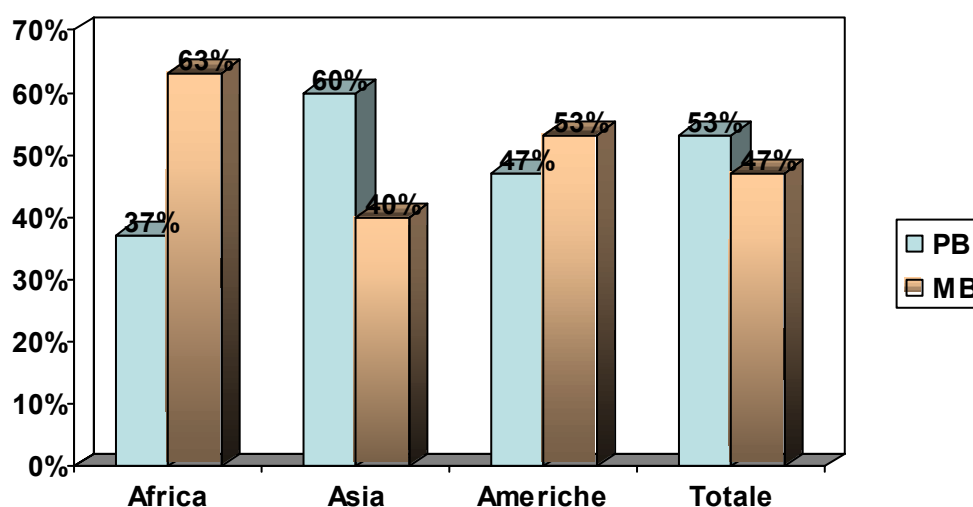
## Beneficiaries of Leprosy Related Activities

Increasingly, AIFO is supporting leprosy related activities through primary health care and community based rehabilitation approaches, at least for direct care. At the same time, there is continuing support for some vertical activities by working in collaboration through Government supported programmes at state/province/district levels, as in Yunnan province in China, many districts in India, Luanda province in Angola, four states in Brazil, etc. Finally at national levels, AIFO is working through national programmes of leprosy and tuberculosis control in countries like Mozambique, and Guinea Bissau, while in Ghana, national leprosy control programme activities are integrated in primary health care.

During 2004, AIFO supported projects diagnosed and treated more than 40,000 new cases of leprosy. Let us have a look at some other data regarding these persons, subdivided from three continents (Asia, Africa and Latin America).

**Geographical Distribution:** More than 20,000 new cases of leprosy, that more than 50% of all new cases of leprosy diagnosed and treated in AIFO supported projects were in India. About 32% of all new cases were in Brazil and about 15% from different countries of Africa.

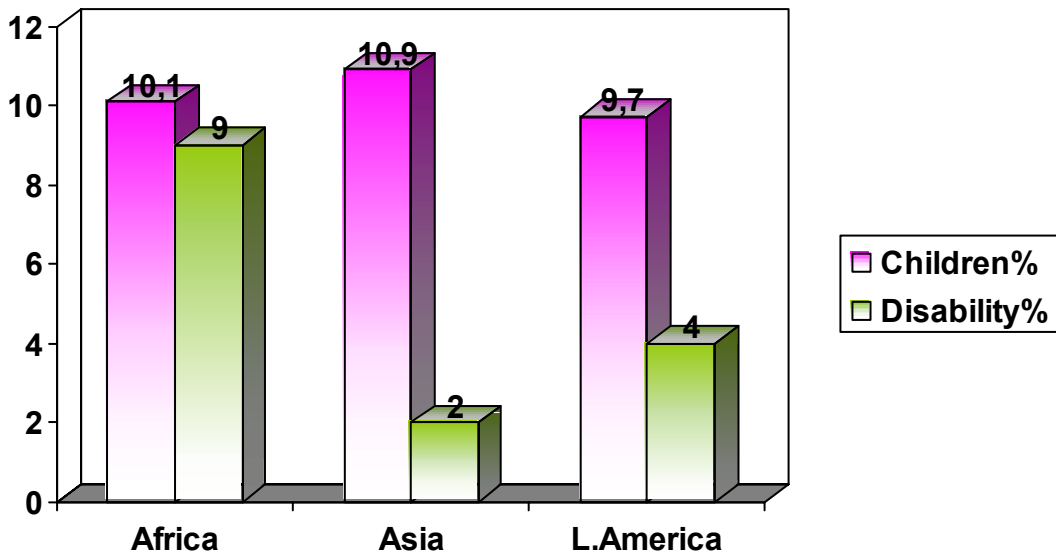
**Multibacillary and Paucibacillary leprosy among new cases:** The following graph shows the situation in the AIFO supported projects in the three continents.



As can be seen from this graph, in both Africa and Latina America (Brazil), MB cases are more than PB cases while in Asia PB cases are more than MB cases.

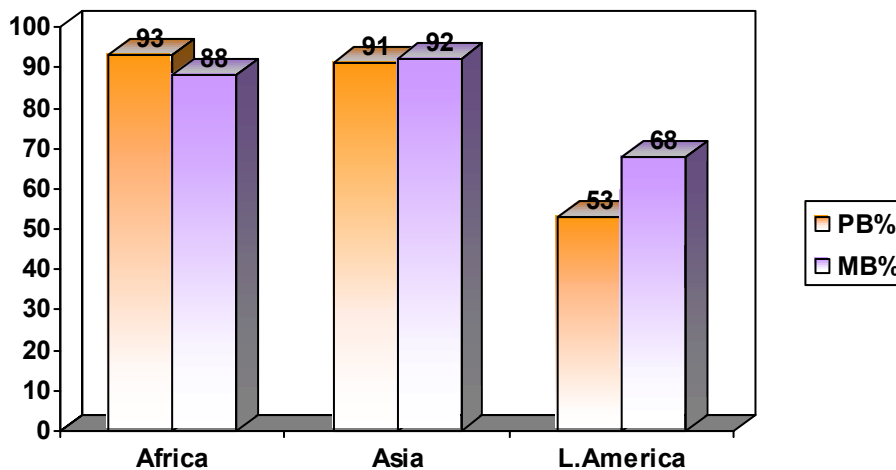
**Children and Grade II Disability among New cases:** Both, percentage of children and percentage of persons with visible disabilities (WHO Grade II disability) are useful indicators to assess the leprosy situation. While the child leprosy rate is an indicator of risk of infection in a community, disability grade II rate serves as an indicator for the efficiency of a project to identify the new cases in an early stage. Both these indicators show an almost stable situation in AIFO supported leprosy projects.

While overall data remains stable, separating the data for continents shows a varied picture for the disability rates, as seen in the next graph.



This graph shows that risk of infection for communities remains high in all the three continents while projects need to improve their early case finding activities in Africa.

**Treatment completion:** It is not enough to diagnose early all the new cases of leprosy but it is equally important to make sure that they take regular treatment with MDT and complete it within the prescribed time (12 months treatment for MB cases to be completed within 18 months and 6 months treatment for PB, to be completed within 9 months). The next graph shows the situation of treatment completion in AIFO supported projects during 2004.



As can be seen from this graph, treatment completion remains a problem in Latin America (Brazil). Evaluation visits carried out by AIFO in Brazil showed that the problem is complex and lack of treatment completion is due to two kinds of problems: (a) Persons not abandoning MDT: Many municipalities do not have any service for MDT distribution and persons need to travel to other municipalities. In such areas, the

abandonment of treatment occurs more frequently. (b) Sometimes, personnel involved in leprosy treatment feel that 12 months MDT is not sufficient for MB cases and decide to continue the treatment beyond the period prescribed by WHO.

AIFO is committed to strengthen its support to leprosy programmes in Brazil. For this reason, since 2002 it has been organising annual meetings of the 4 states where it supports the state leprosy programme (Acre, Bahia, Goias and Par ). These meetings involve representatives from priority municipalities of these states by rotation. Dr Maria Leide, from university of Rio de Janeiro has been collaborating with AIFO's representative, Ms. Deolinda Bittencourt in this initiative.



Dr Maria Leide (right) providing on the job training during a field visit in Bahia

**Other Medical Care Activities for Leprosy Affected Persons:** AIFO promotes global view of problems facing leprosy affected persons and does not limit its work to diagnosis and treatment with MDT. Thus the medical care activities supported by AIFO include prevention of disabilities, rehabilitation and care for complications of leprosy. Recently AIFO prepared a new monitoring form to collect information about such activities that was tested in some of the projects. This monitoring form will be adapted on the basis of information received for 2004 and will be extended to all projects supported by AIFO from next year.

The salient features of the information regarding other medical care activities collected from the projects for 2004 are as follows:

- Generally speaking projects are not aware of all the persons treated with MDT for leprosy in their areas and thus their knowledge about their other needs is fragmented and limited. Most of the time, projects provide services to those who come to them.
- Projects rely of "word of the mouth" publicity rather than on specific communication strategies to create awareness among leprosy affected persons regarding the possibility of footwear for persons with insensitive feet or about operations for surgical correction.

The partial data collected for these activities showed that 43,291 persons received the following services (it is possible that some persons are counted more than once as they may have benefited from more than one service):

- Eye care and eye operations: 1,406
- Care for neuritis and reactions: 3,197
- Plantar ulcers: 10,207
- Other surgical operations: 367
- Protective footwear: 1,808
- Dressings: 14,525
- Care for persons living in old leprosariums: 923
- Other care: 10,799



A person with leprosy related disabilities doing self-care activities to prevent worsening of disabilities in Luanda province (Angola)

**Activities for Socio-Economic Rehabilitation (SER):** AIFO promotes activities for socio-economic rehabilitation of leprosy affected persons through participatory approaches that empower persons to make their own choices and responsibilities for their own care and development. In this regard working together with associations of leprosy affected persons is a key area for AIFO's work. At international level, AIFO has been actively collaborating with IDEA (International Association for **I**ntegration, **D**ignity and **E**conomic **A**dvancement) as well as with associations of leprosy affected persons at national levels (in Yunnan-China with Handa, in Bahia-Brazil with Morhan, in Luanda-Angola with Arpal, etc.). During 2004, a visit by an IDEA delegation from Brazil and Angola was organised in Mozambique for promoting the launching of similar Mozambican organisation.

The SER activities supported by AIFO are directed mainly at leprosy affected persons and their families. However, these activities can also benefit other marginalised groups in the society, especially persons with disabilities and other poor persons. The SER activities in AIFO supported projects benefited 10,106 persons in 2004 in the following manner:

- Occupational training: 360
- Loans for self-employment: 981
- Persons in sheltered workshops: 279
- Loans and grants for house repair and construction: 162
- Support for formal education: 1,401
- Support for informal education: 1,305
- Social welfare and assistance: 3,013
- Counselling: 2,605



Leprosy affected women from a minority tribe in Yunnan province (China)

### **Beneficiaries of Primary Health Care Activities**

As increasing number of leprosy projects supported by AIFO are integrated with primary health care (PHC) services, during 2005 a new AIFO monitoring form for collecting information about these activities. This form was tested in a limited number of projects for collecting information related to 2004. This monitoring form will be further refined and extended to all projects involved in PHC activities from next year. Meanwhile the partial data collected for 2004, showed that 113,778 persons benefited from these services during 2004, in the following manner:

- Malaria: 5,177
- Respiratory infections: 5,573
- Diarrhoea: 3,788
- Antiretroviral treatment for persons with HIV/AIDS: 2,039
- Vaccinations: 2,906
- Antenatal care to pregnant women: 3,977
- Dermatological diseases: 42,302
- Other tropical diseases: 479
- Intestinal parasites: 5,449
- Tuberculosis: 34,577
- Malnutrition & anaemia: 3,853
- Others: 3,658

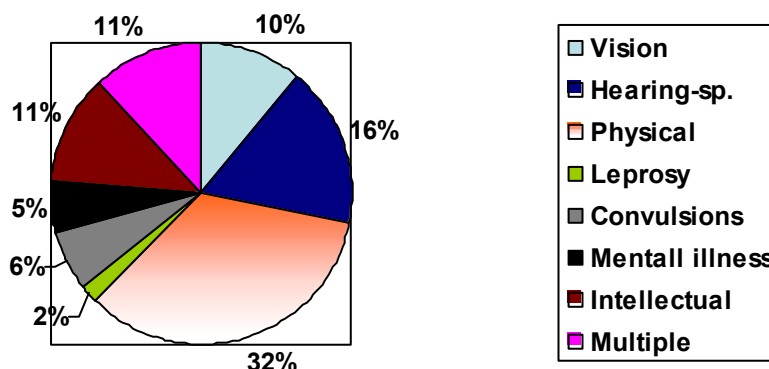
### **Beneficiaries of Community Based Rehabilitation (CBR) Activities**

During 2004, the CBR projects supported by AIFO provided some support to 47,751 persons with disabilities and about 27% of these beneficiaries are children. Receiving timely reports and monitoring forms from some of these projects has been a problem. For this reason, the data about beneficiaries of CBR projects is partial.

A more detailed analysis of the monitoring forms shows some interesting findings.

Beneficiaries of CBR projects according to the type of disability: The following graph shows the percentage of persons with different kinds of disabilities among the beneficiaries of CBR projects supported by AIFO. The aggregate data shows that all groups of disabled persons are represented in the projects including persons with the

so-called "difficult disabilities for CBR" such as, hearing and speech disabilities (16%), leprosy (2%) and mental illness (5%).



Deeper analysis of project monitoring forms shows that projects may specialise in working with certain kinds of disabilities. Thus while Alexandria CBR project in Egypt has a much higher percentage of beneficiaries with intellectual impairment, Cochin in India has a higher percentage of persons with mental illness. This goes against the common perception that CBR is not useful for certain groups of disabilities.

**Promoting Empowerment through CBR:** CBR projects can promote empowerment of persons with disabilities and their families in different ways including by working with disabled persons as CBR workers, by promoting a culture of decision-making by disabled persons themselves, etc. Two specific activities can be taken as an indicator for empowerment promotion activities: promoting persons with disabilities to meet together, to share experiences for creating (a) self help groups and (b) local organisations of disabled people (DPOs).

During 2004, in AIFO supported CBR projects, there were 726 self-help groups with 11,228 members and 378 community level DPOs with 5,087 members.



A roadside restaurant run by a cooperative of disabled persons in Eritrea

**Promoting access to existing services:** An important part of the CBR philosophy is to promote access of persons with disabilities in existing governmental and NGO run

services rather than setting up additional parallel services. During 2004, AIFO supported CBR projects facilitated persons with disabilities to access the following services:

- Artificial limbs and mobility aids: 1,615
- Specialist visits: 6,000
- Surgery: 152
- Going to school or university: 1,420
- Receiving pension certificates: 39,359
- Other services: 2,923



On World Disability Day 2004, Mandya project (India) helped persons with disabilities in their project area to get 200 free wheel chairs from the Government of India

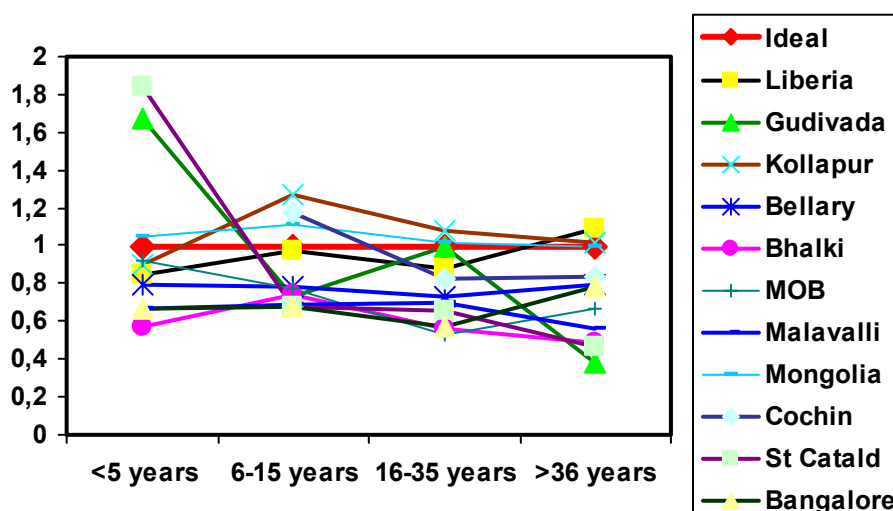
**Providing services to persons with disabilities:** In addition to promoting access to existing services, CBR projects also organise some services directly. Most such services are linked to home visits for training disabled persons and/or their family members for activities of daily living, local production of low-cost aids made of local materials, etc. During 2004, the CBR projects supported by AIFO provided the following services to persons with disabilities:

- Artificial limbs and mobility aids: 2,252
- Physiotherapy support: 5,507
- Home visits by CBR workers and volunteers: 22,398
- Non-formal education: 2,535
- Formal education: 1,368
- Occupational training: 797
- Loans for self-employment: 972
- Other services: 4,854

Beneficiaries of the CBR activities according to gender: Access of CBR services to women and girls with disabilities has been a concern in AIFO. In 2005, AIFO's CBR form was modified to ask for information according to gender. The analysis of the data received for 2004, even if incomplete, presents a clear bias against women and girls with disabilities as beneficiaries of CBR activities.

The graph on the following page shows the analysis of this data. This analysis considers that ideally men and women should benefit from CBR activities equally (red coloured line in the graph). The male to female ratio among the beneficiaries was

calculated and plotted on the graph. If number of women beneficiaries is higher than men, then their line will be above the "ideal" line. If the opposite is true, that men benefit more than women, then their line will be below the ideal line.



As can be seen from this graph, except for two projects (Mongolia CBR and Kollapur-India) majority of projects have differing degrees of inequalities in terms of access to women and girls with disabilities. A few projects such as in Liberia, St. Catald – Nuzvid, India, Cochin-India and Gudivada-India, may have more access to women and girls for specific age groups but it is not consistent. This will be one area in which projects will be asked to reflect.

### Beneficiaries of Projects Aimed at Vulnerable Children

Usually projects dealing with vulnerable children are also engaged in leprosy related or disability activities, also supported by AIFO. During 2004, children benefiting from specific activities were as follows:

- School uniforms: 1,844
- School books and notebooks: 2,331
- Scholarships: 780
- School fees: 1,013
- Inclusive education: 95
- Occupational training: 21
- Nursery schools: 1,531
- Health check-ups: 3,237
- Counselling: 523
- Vaccinations: 438
- Mobility aids: 57
- Dental care: 559
- Food supplements: 3,998
- Cultural & creative activities: 1,005
- Others: 1,026

## Conclusions

AIFO has chosen to focus its work on poorest and most vulnerable population groups. In different countries, projects supported by AIFO are in isolated and difficult to access areas. With time, increasingly AIFO supported projects are involved in promoting integrated activities where the fight against leprosy is linked with community health and primary health care activities. AIFO continuously strives for best uses of resources that can impact more persons through approaches that include promotion of participatory development, empowerment, human rights, inclusion, appropriate technologies, use of local resources, community involvement, etc. All activities supported by AIFO are monitored and evaluated regularly to ensure best use of its resources.



Persons working at AIFO Head-office in Bologna (Italy)