LEPROSY IN A CHANGE CONTEXT

The place of leprosy
in present day national health systems

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Introduction 1

**Integration of leprosy services** recommended by WHO Working Groups and Expert Committees

**National health systems**/ national health care systems consist of: all organizations, people and actions with primary intent to restore or maintain health in the target population.
Introduction 2

• The **Elimination strategy in early 2000** led to dramatic decrease in numbers of patients registered for treatment.

• Countries now have to **sustain leprosy care activities** for an indefinite period (as eradication may not be feasible in the foreseeable future).

• Global Strategy 2006-2010 emphasized **reduction of reliance on vertical programmes** and promoting integration.

• The current strategy 2011-2015 stresses **sustaining political commitment** and strengthening routine and referral services within the integrated health systems in all endemic countries.
Integrated leprosy services should be provided:

• in multipurpose settings,
• by health workers in the general health services
• Including all essential leprosy control activities and referral services
Purpose of the presentation

• Review of the experiences gained (in Uganda and a few other countries) in management of leprosy within the general health system and discusses options for the way forward.
Leprosy as part of health system: Present situation

- New case detection continues with increasing detection delay, new child cases.
- Leprosy included in the Health Sector Strategic Plans:
  - Not in the list of priorities
  - Part of a combined programme with TB and TB/HIV
  - Appearing on the list of NTD, or diseases targeted for elimination or even eradication
  - Included in the curricula of health Training Institutes (not always being taught)
National leprosy control strategies

Strategies engaged by national health systems for leprosy:

(i) Combined programmes with TB, TB/HIV (Uganda, Kenya, Tanzania, Nigeria, Sierra Leone, Madagascar)

(ii) Continuing with leprosy control / elimination programmes as stand alone entities in high burden countries (DRC, India)

(iii) Combining leprosy care services with dermatological services (Egypt)

(iv) Integrating ALL aspects of leprosy treatment and care into general health services The ideal.
Challenges across the strategies

• Skilled human resources (quality, quantity)
• Prioritization based on numbers
• Organization of Integrated supervision
• Collection and utilization of monitoring data
• Prevention of disability; training for self care and management of home care services
• Organization of integrated referral systems
• Management of rehabilitation services
Roles of different players in the health system: **Government / MOH**

- **Policy formulation** including ensuring effective integration and monitoring and evaluation of the services. NTDs
- **Recruitment** of programme staff (general and specialist) and ensuring a functional referral system
- **Training**
- **Supervision** to ensure quality services including rehabilitation
- **Providing infrastructure**
- **Procurement of medicines and other supplies** and assuring access
- **Organizing programme for prevention of disabilities**
- **Organizing or participating in operational research**
Roles of different players in the health system: Partner organizations

- Funding of operational aspects
- Technical support for (policy formulation, M&E)
- Implementation of projects
- Training
- Provision of specialist/referral services
Roles of different players in the health system: Health facilities and Health Service Providers

• Accepting to undertake leprosy related activities  
  • Diagnosis  
  • Treatment  
  • Management of complications  
  • Community sensitization  
• Undergoing relevant training  
• Participating in collecting monitoring data
Roles of leprosy affected persons and their families/communities

• Participate in policy formulation
• Referral of suspect cases for diagnosis
• Support for those on treatment
• Organisation of self care groups
• Advocacy
• Participate in operational research
Lessons learnt: Governments/MOH/ National Programmes

• Just declaration of government commitment/support is not enough: e.g.
  • written political commitment not always accompanied with financial commitment
  • Combined programmes without representation of leprosy portfolio in national administrative hierarchy
  • Lack of realistic presentation of costs relating to management of referrals.
Lessons learnt 2

• Leprosy included in plans but without budgets
• Decision makers are overwhelmed by other competing health problems e.g. in Uganda 267 new leprosy cases, 49,000 new TB, 200,000+ new HIV infections etc.
• High risk populations are not yet rid of “traditional issues” like: soil transmitted helminthiases, diseases related to water and sanitation.
Lessons learnt: Governments/MOH/ National Programmes continued

• Talking about the diminishing knowledge and skills of health care providers without planning for sustaining them does not solve the problem.

• When training of various categories of health workers is undertaken without considering the real needs of the programme; many people will get trained but very few will actually participate in service delivery

• Leprosy training included in curricula sometimes does not take place or is not appropriate

• M&E: Routine data collected through HIMS can filter through without attention. Minimizing the quantity might not positively impact on quality and use.
Lessons learnt: Governments/MOH/ National Programmes continued

- Integrated supervisory activities do not always meet the basic requirements of the leprosy component.
- Engagement of leprosy affected persons in programme management remains a “missed opportunity”
- Research: understand its great value but do not invest befitting time and money. Partnerships??
Lessons learnt: Roles of Health facilities and health workers

- There is still poor adherence to the ideal integrated setting where “leprosy treatment takes place inside public health facilities and the service providers are the same ones who take care of other health related responsibilities”
- Only diagnosis and treatment services have been integrated. Secondary level care in the hands of specialized vertical programmes. Possible disadvantages of this approach...
Other lessons learnt

• Specialized services could hinder the integration process
• Quality regulation of referral facilities operated by private or private-not-for-profit organizations is necessary
• Leprosy related disability care within integrated general health systems is feasible and sustainable.
• Strategies for prevention of disabilities and CBR are essential for improving the quality of life of leprosy affected persons
• Many integrated programmes are not adequately addressing the rehabilitation needs of leprosy affected persons (both Medical and Social Economic)
Yes, there is a place of leprosy in the health system as an integral part; It should be sustained by:

• continuing to recognize it by name as health and social problem:
• Following the WHO recommendations on integration to ensure local adaptation in terms of implementation; focus on the actual needs of leprosy affected persons in terms of access and quality of care (numbers of cases only not enough)
• Engage leprosy affected persons as per agreed WHO guidelines
• Updating the content of training curricula and monitoring implementation
• Implementing referral systems (institutions and individuals)
• Promoting basic and operational research, (building evidence, developing tools, testing tools)
• Addressing issues of stigma and discrimination.
Remain mindful that:

In leprosy endemic countries, it (leprosy) remains an integral part of national health systems (by definition)

“Leprosy systems” that are not well embedded into national health systems are likely to die out pre-maturely.

Sad but true ?: some quite excellent vertical projects might die out at the end of the project period while “integrated mediocrity” although slow, is more likely to last
Whatever the place of leprosy might be..., what matters most remains that:

“All leprosy affected persons wherever they are should have an equal opportunity to be diagnosed and treated by competent health workers, without unnecessary delays and at an affordable cost”
Thank you