The Prevention of Leprosy Related Disability as an Integral Component of the Government Health Delivery Programme in Indonesia: Perspectives on Implementation

HUGH CROSS
American Leprosy Missions, 1 ALM Way, Greenville, SC 29601 USA

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Summary This paper presents a record of three interviews with groups of Ministry of Health personnel and consultants that took place in Jakarta, Indonesia in May 2012. Those contributing to the first interview were provincial and district supervisors with responsibility for leprosy. Those contributing to the second interview were consultants, three of whom were seconded to the Ministry of Health and one was a WHO consultant. A third interview was conducted with the Head and a technical staff member of the Sub Directorate of Leprosy and Yaws Control Programme, Ministry of Health, Indonesia.

Leprosy control in Indonesia had been targeted for further enquiry after it became apparent, through an earlier survey of national programme managers and consultants, that the programme had been relatively successful in integrating POD into the government health delivery programme. The perspectives of significant representatives and actors in the national programme were recorded through the interviews undertaken in Jakarta.

Limitations This report does not purport to be a study of integration of leprosy services in Indonesia. The perspectives of representatives and significant actors are offered here to enhance understanding of factors that contributed to POD becoming a routine component of general health care in Indonesia. It is also declared here that no independent verification of statements was undertaken and that the effectiveness of measures taken to integrate leprosy related POD has not been independently evaluated.

Introduction

In 2009 a multinational survey of leprosy programme managers and consultants was undertaken and salient findings from this were published in 2010.1 One of the objectives of the survey was to ascertain which national programmes had managed to implement or
influence the implementation of robust prevention of disability interventions (in some countries leprosy prevention of disability is an integral component of other health programmes). Under the terms of the survey, programmes were deemed to be well placed for the provision of prevention of disability (POD) interventions if the following essential criteria were reported:

- There is a person, or group, with specific responsibility for POD, who facilitates improvement of POD coverage through a Government programme in the country.
- There is a specific action plan for POD that has been developed / implemented through a Government programme.
- An assessment of the extent of leprosy related disability (focal or national) or specific plans to conduct an assessment of extent of leprosy related disability (focal or national) has been undertaken.
- There are specific plans for POD-related operational research in the country supported by the national programme.

In an attempt to ensure consistency there were a number of questions relating to each criterion, answers to which gave clearer definition to each of them. None of the 23 programmes considered fully satisfied all the criteria but the Sub Directorate of Leprosy and Yaws Control Programme, Ministry of Health, Indonesia was one of four programmes that reported characteristics that satisfied most of the essential criteria.

Between the 24th and 27th of April 2012, the author held three group interviews. The first was with five provincial and district supervisors who have responsibility for leprosy. The second was with three national consultants and a WHO consultant, who guide the national programme in policy decisions and assist with training, monitoring and supervision activities. The third interview was with the Head and a Technical Staff member of the Sub Directorate of Leprosy and Yaws Control Programme, Ministry of Health, Indonesia. All interviewees had contributed to the development and implementation of POD at planning and/or operational levels. The objective of the interviews was to record lessons from their experience that might prove to be informative for other national programmes. Prior permission to conduct and record the interviews had been obtained through the office of Dr Dianne van Oosterhout, Netherlands Leprosy Relief (NLR) Representative, Indonesia, who also assisted with the logistics of the project.

Three independent interviews were conducted. The interviews were recorded on a voice recorder and were transcribed at a later date. The transcriptions were edited to capture salient responses and explanations. Extraneous contributions were cut to condense the report and to minimise obfuscation. The results presented below are a composite of responses from the three groups to the same essential questions. The questions are reported verbatim. The responses were further edited for clarity of presentation, but the intended messages were not changed.

The names of the contributors to the interviews are disclosed an Appendix 1. A diagrammatic representation of the structure of health services in Indonesia is presented in Appendix 2.
Interviews

HC: – How did POD come to be considered important in the National Programme?

“It goes back to 1996. There was a leprosy consultant from NLR, Dr Arie de Koning. He gave a five day training on POD in Maluku. That training had a strong focus on nerve function assessment although by that time the treatment of reactions was already considered to be necessary for leprosy control. It was on de Koning’s instruction that we learned how to encourage people to do self-care. At that time the idea was first to demonstrate self-care, then to do it together with patients and then to observe them doing it themselves. The training given then was very comprehensive at the time, but it didn’t include socio-economic rehabilitation. Dr de Koning came again in 1998 and at that time he was training health post staff in Makassar. He also introduced a booklet on all aspects of POD that was based on Watson’s book on the subject. So, the concept of POD had been given official recognition in 1998, but at national level it really began to feature in about 2003 to 2004 when it was included in the National Guidelines of 2004. With inclusion in the national guidelines POD became mandatory.

“In 2000 a project leader and a project coordinator (both from the province of West Java) were sent to Ethiopia to learn about home-based self-care groups. They returned to initiate self-care groups in their province. That initiative was then promoted by NLR, which also financially supported the concept, and consequently other provinces became inspired to follow. At that time NLR also dispatched a medical advisor, Dr Jacqueline Gravendeel. She and Dr Teky Budiawan went to district Subang in West Java to learn about the concept of self-care groups and Dr Teky then set up the first 4 self-care groups in his province, which is North Sulawesi. Another medical advisor followed, Dr Marion Steentjes, she helped to further develop the concept and then NLR tasked Kerstin Beise with starting self-care groups in Makassar, in South Sulawesi.

“Before self-care groups began in 2001 in North Sulawesi, medical rehabilitation (reconstructive surgery) was already offered in Leprosy hospitals and there was a growing knowledge of POD in those hospitals. So POD in terms of reconstructive and septic surgery were already established as services, but it was in 2004 that the concept of home-based POD really started to become a reality. It was then that technical officers in the provinces started to become aware of the wider application of POD. During these developments Dr Yamin Hasibuan (NLR) had responsibility for what was termed “rehabilitation”. He was responsible for supporting leprosy hospitals to develop services for secondary complications (prevention of worsening disability).

“When I joined the national programme in 2002, POD was not actually given much importance. Focus was on leprosy as a public health issue. The importance of POD began to emerge gradually, but by 2004 it had become familiar to all the programme managers and technical officers in the provinces. It was then that POD was put in the national guidelines. Nerve function assessment had already become established practice in the Health Centres.”
HC: Did the stimulus for this thinking come from the national control programme or did it come from elsewhere?

“The concept and initiative came from NLR but it could only spread because of the commitment of the national programme. It was also NLR that was asked to help to develop and assist in the implementation of initiatives to spread the model of self-care group establishment which had started in West Java. They needed a model that could be implemented throughout Indonesia.”

HC: How did the awareness of that project spread?

“It spread through the involvement of the national consultants who visited places where self-care groups were successful. They then took the model back to other provinces. It was really stimulated by NLR from consultant to consultant. It was later that we attempted to get the model for self-care group establishment into the national guidelines. It was actually essential that this should happen. The concept had to be in the national guides before it could be given approval for implementation in any other provinces.

“Self-care groups began in the provinces supported by NLR but there had also been a gradual implementation of the model in other provinces too. Of course there was NLR financial support in the provinces they supported and this is how it could be implemented more smoothly and quickly in those provinces.

“We have been talking primarily about the implementation of self-care groups, but that is not the most important development. Self-care groups are only a small part of POD in the country, there are as yet relatively few self-care groups. What is more important is that Health Centre staff are interacting with patients and giving them advice about self-care to do at home, and this is happening everywhere even where there are no groups. In my opinion, if there is to be good POD there should be a strong focus on building capacity at Health Centres rather than self-care groups.”

HC: Health Centres are not under direct control of central government, they are responsible to local authorities so how are they motivated to implement POD?

“The extent to which they are motivated is largely a reflection of the actions of the project leaders. NLR funds the appointment of a person (project leader) from each province who is responsible for taking relevant information from central to district level and then district level staff disseminate the information to the Health Centres. This is closely monitored. These project leaders give clinical guidance, they also give transportation money, for the Health Centre staff to go to training where the importance of POD is promoted – they also try to ensure that the importance of early case finding, nerve function assessment and prompt treatment of reactions, are well understood and accepted.

“Directives go to project leaders and provincial supervisors who are responsible for delivering technical support and guidance to Health Centre staff. It is then the district supervisor’s responsibility to monitor implementation and to assist the provincial
supervisors. The district supervisors visit the Health Centres regularly so that when problems are identified the supervisors can give immediate assistance.

“Supervision duties are very important for Health Centres. Every year we come up with better quality service indicators – we now collect information about additional disabilities during treatment. We have just piloted an initiative to supervise people affected by leprosy after RFT. We are also trying to record motivation to do self-care and access to care and referral when it’s needed because we recognize that some people only become disabled after treatment. Now we are working on spreading an understanding of that issue through our supervision activities.

“We started recording disability data about 10 years ago. That may have contributed to health workers becoming more aware of the problem of disability. EHF was not recorded 10 years ago but worsening disability was recorded. With the introduction of EHF we were able to motivate staff, not only by congratulating them on the quality of work but also by showing their performance against the indicators. At Health Centres, five years back, they started collecting EFH scores at diagnosis and RFT, since then we started to use the EHF scores in our cohort analysis (that was when the electronic database was established).

“We do have quality of service indicators, but more importantly, we collect the data so that we can keep contact with Health Centres that need help. We are establishing a system so that people who do have reactions or other problems after RFT are not lost and that they do get appropriate treatment (this is the pilot study that was referred to earlier). Health Centres will be keeping surveillance of people at risk for five years after RFT. People at risk are those with a history of reaction, those who had a high BI and those who already had disability before treatment.

The responsibility for collecting that data and for monitoring patients’ progress will be with the Health Centres. At the moment this is still only being piloted in two districts in two provinces with all Health Centres in those districts participating; it has been a two year pilot study to see if heightened surveillance will reduce impairment. The data is still being analysed but it seems to be working so we are now discussing how to replicate the model operationally.

“It’s very important to motivate the health workers in the periphery. What I usually do is appeal to their humanity. I appeal to the heart and also remind people of the heavenly rewards that await people who conduct services for the poor. It is important to have regulated policies, but leprosy work will always need personal conviction and dedication.”

“Motivation is largely an effect of personal responsibility and pride. We always emphasize how disastrous it is for patients if they have developed Grade II disability during treatment. There is also the situation with indicators: worsening disability indicates poor programme performance and people do not want to be associated with poor performance. There is also a culture of helpfulness in our country. When we see the plight of people affected by leprosy we feel pity for them and feel it is our duty to help them. It is part of our spirituality.

“We Indonesians, particularly in rural environments, have a culture of ‘helping each other’ (gotong royong). This is definitely one of the reasons that there is success with self-care groups in Indonesia. In rural contexts it is in people’s hearts to help one another. It’s understood that if a person is affected by leprosy and has disability he won’t have money to live comfortably. At such times friends are eager to help him to form a group so that he might get help and that the group members can help each other.”
HC: In terms of POD what are the requirements for the health workers at Health Centre level to record?

“Disability grading (EHF Scores) at start and end of treatment. VMT/ST is recorded as are wounds, contractures and other impairments; it’s quite detailed. The health workers do not generally complain about the work required, but they do complain when there are moves to modify the reporting requirements. One of our problems is that we have a very large country with so many Health Centres so it’s not easy to get information about changes to all Health Centres in a timely manner. It can happen that by the time information reaches some health posts there has already been a message for further change. The main point is, get the patient card up to the appropriate standard required initially and then don’t change it.”

HC: What does the government do to ensure that capacity is developed and maintained?

“They have organized national level training from the leprosy training centre in Makassar to maintain quality. This is done routinely but the frequency depends on the budget, sometimes three times a year for different batches. There are also coordination meetings which are conducted at district, provincial and national levels. Data are presented and discussed and there is also a general sharing of experiences at those meetings.”

HC: It has been stated that the extent to which POD could be integrated in Indonesia was much greater because the country has a decentralized system. Please can you clarify how this is an advantage?

“With self-care groups, for example, at district and Health Centre level they have a strong sense of ownership of the programme because they have actually chosen to set up the groups themselves the decision was not imposed on them from any remote central authority. This is why advocacy is so important.”

“One disadvantage is that leprosy control is not always a priority. Local authorities set their own priorities and that does not usually include leprosy. If the leprosy control teams from the province cannot promote the importance of leprosy then they will not get sufficient budget from local government to run good programmes that include POD. So the decentralised system is only an advantage where provinces can successfully persuade local governments that leprosy activities really need to be budgeted for. When they are successful in that endeavour, there is good cooperation. It is crucial that the project leader should be a person who will be able to influence what happens at provincial level because that will subsequently influence what happens at district level.”

Question put to Provincial and District Supervisors only: “What motivates you to do the work?”

- “Having become aware of the stigma of leprosy (through the training I underwent) I feel it is my duty to help such people.”
"Of all the programmes I work in I most like leprosy because I have direct contact with the people and have opportunities to get out into the field away from my desk."

"I had been in HIV AIDS where the basic problem was behaviour, but for people affected by leprosy it is not their fault at all that they get the disease so my motivation is to try and help them before they get any impairments."

"When I started there was an old supervisor who was elderly but really helped people. She was an inspiration to me and I just want to be like her. I also had experiences with contact examinations and saw how the disease seemed to affect whole families of people who were poor and I knew I could help them. I really wanted to help them to prevent impairments."

"We have a very good communication with the central office and that’s important because they keep us updated on latest developments and research. We have annual meetings for supervisors which are conducted by the central office. If there is urgent information the central office will circulate it to us by email."

HC: It was suggested earlier that NLR, together with an active sub-directorate, was the main reason why the programme is successful; if NLR support had not been available would the programme have been as effective?

"It is not really the finance that is important but the concept of POD, the ideas themselves and how they are promoted – that is crucial. For example, district and Health Centre level staff are not obliged to establish self-care groups, but they will be more eager to run them if they know there is an umbrella of law authorizing them to do so. The concept of self-care groups is given mention in the national guidelines of the Sub Directorate for Leprosy and Yaws. This is very crucial. The importance of NLR was that they brought sound ideas, strongly supported by evidence so they could be included in the guidelines with confidence. Because they were authoritative ideas, validated by inclusion in the guidelines, the concepts are respected.

"This is true to some extent but Health Centres cannot implement the concept of self-care if they do not get funds. So it’s both technical and financial influence of NLR that brings about success.

"Yes, it’s also essential to have the national consultants. If there was no NLR support there would not be any national consultants and their responsibilities would have to be undertaken by sub-divisional staff (Sub-Division of Yaws and Leprosy), but there really aren’t enough of them to cover the entire country.

"Actually we have just had a discussion about what cuts could be made. It was clear that supervision activities are essential and that they could not be sustained without external support."

HC: What operational research or health systems research has been done and has this contributed to the development of POD?

"In 2007 a rapid disability appraisal was done in 5 districts. It will be part of the WHO disability report. We are trying to get a measure of the burden of disability. After collecting the data we conducted a debriefing with the head of the provincial head office
and there was further discussion about what to do about the situation, what sort of services were required. It raised an awareness of the situation for people affected by leprosy in those districts.”

HC: If you were to offer advice to leprosy programmes in other countries that are trying to develop good POD implementation, what would that advice be?

“In large countries like Indonesia the most important advice is to focus on advocacy at the levels of local and central government simultaneously. Choosing the key people for this will be the leprosy programme manager’s responsibility.

“Collaboration with other sectors is necessary because a government may have the commitment but not the resources to develop and sustain POD as an intervention. It requires the cooperation of national and international NGOs and the involvement of the private sector with the government to integrate these services successfully.

“What is being done through the consultants and others should be emphasized and further developed. There needs to be a regular mentoring of the Health Centre staff. They need to be constantly updated on NFA and self-care, these issues can so often be neglected or left out when supervision is done. At lower levels, constant technical input is needed especially where there is very frequent turn-over of staff.”

Conclusion

The opinions and perspectives of the personnel interviewed for this investigation added depth to the findings of a survey, the results of which suggested that POD had successfully become a component of general health services in Indonesia.

Acknowledgments

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References

Appendix 1
## Appendix 2: Interviewees

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<th>Name</th>
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<tr>
<td>Dr Christina Widaningrum</td>
<td>Head, Sub Directorate for Leprosy and Yaws</td>
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<td>Mrs Tiara Pakasi</td>
<td>Officer, Sub Directorate for Leprosy and Yaws</td>
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<tr>
<td>Dr Teky Budiawan</td>
<td>National Senior Consultant, Leprosy and Yaws</td>
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<td>Dr Firmansyah Arief</td>
<td>National Disability and Rehabilitation Consultant</td>
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<td>Dr Benjamin Sihombing</td>
<td>WHO Consultant, Neglected Tropical Diseases</td>
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<td>Mrs Kerstin Beise</td>
<td>NLR – Disability and Rehabilitation Consultant</td>
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<tr>
<td>Rini Susiati</td>
<td>Provincial Supervisor (Wasor) West Java</td>
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<td>Upi Meikawati</td>
<td>Provincial Supervisor (Wasor) Banten</td>
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<td>Solihatun</td>
<td>District Supervisor (Wasor) DKI Jakarta (district East Jakarta)</td>
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<td>Rita Aryati</td>
<td>District Supervisor (Wasor) West Java (district Subang)</td>
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<td>Ipah Adelah</td>
<td>District Supervisor (Wasor) Banten (district Serang)</td>
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