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Title: Effective mainstreaming rehabilitation of leprosy affected persons in CBR for persons with disabilities: evidence from Myanmar

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PAPER

Abstract

Analysis of data from Myanmar demonstrates that people affected by leprosy included in mainstream CBR programmes have significantly higher rates of improvement of economic and mobility outcomes compared with other persons with disabilities receiving a similar package of interventions. Cost-benefit analysis demonstrates that mainstream CBR programmes can deliver benefits to people affected by leprosy with similar or superior cost-effectiveness that leprosy-specific programmes.

Background

Evidence that persons with disabilities, including those affected by leprosy, are disproportionately affected by poverty is well known,[1] and evidence points to increased rates of poverty of households with members affected by leprosy.[2] Inclusion of people affected by leprosy into mainstream Community Based Rehabilitation programmes draws on the basis of human rights principles, ultimately seeking to ensure that leprosy-affected persons are enabled to realize their rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). WHO's operational guidelines for leprosy programme state clearly that 'It is not only pragmatic but beneficial for people affected by leprosy to be integrated into programmes that may already have been established for the rehabilitation of other disadvantaged people.' [3]Although recent guidelines emphasize the need to pursue integrated, rather than exclusive programmes for the rehabilitation of people affected by leprosy[4], there remain concerns that people affected by leprosy offered rehabilitation in mainstreamed CBR programmes have inferior outcomes and continue to suffer stigmatization.[5] Likewise, robust comparisons of the cost-effectiveness of mainstreamed compared to specialist programmes are not available.

Method

This paper analyses field data from a sample of 593 beneficiary households included in mainstreamed CBR programme activities undertaken by the Leprosy Mission Myanmar between January and December 2011. Cost effectiveness comparison is made with a sample of 250 beneficiary households receiving rehabilitation through a leprosy-specific programme undertaken by the Leprosy Mission Myanmar between January 2008 and December 2009. The Leprosy Mission Myanmar adopted a broad, inclusive policy towards disability from 2004, with the first genuinely inclusive services being implemented in 2007. Following the 2008 Nargis Cyclone, TLM Myanmar assumed a leading role in the disability movement in Myanmar, working in collaboration with government ministries to undertake a national survey, policy development and expansion of service provision, initially to disabled victims of the Cyclone, and later across over half of the administrative districts in Myanmar. Project data examined here is derived from activities in the Delta Region and in Mon State. The following indicators were used:

Socio-economic indicator: Economic vulnerability score. This is designed to identify and measure change amongst those who are most at risk of adverse impact of changes to their economic situation. Interview of household determines the score for each category, and then a total score is allocated.

Figure 1: Parameters for Economic Vulnerability (EVS) Score

Score → Factor	-2	-1	+1	+2
Land/house ownership	Homeless	Rent House	Own House	Own Land& House
Assets (Pig, Cow, Trishaw…)	Nothing	Personal Possessions only	Few assets (e.g. 1 pig, 2 chickens etc.)	Large assets (e.g. >1 pig, trishaw etc.)
Job (Yes/No)	No income	OK/irregular	OK/regular	Good/regular
Dependents (family members not generating income)	More than 4 dependents	Between 2 and 4 dependents	1 or 2 dependents	No dependents
Debt (Yes/No)	More than Kyat 100,000	Kyat 30,000 – 100,000	Kyat 0 – 30,000	No debt

Social participation: Community Participation Index: participants indicate the degree to which they participate in the activities and decision making processes of the community; narrative is transferred into a score by means of 'best fit' to the following categories:

Score –2: participant feels excluded from most community activities, including social events, decision making processes and some daily events

Score –1: participant feels excluded from some community activities, but is included in others. He/she feels excluded from decision making processes

Score 0: participant participates in most community social activities with few restrictions, but is not generally included in decision making processes

Score 1: participant participates in most, if not all, community activities with few restrictions, and is often included in decision making processes

Score 2: participant participates in most, if not all, community activities with few restrictions, and is a leading voice in decision making processes

Rehabilitation: MAO Score (Mobility Access Opportunity): participants indicate the degree to which they can access viable work, are able to move around in their community, and are able to participate in society.

Figure 2: Parameters for Mobility, Accessibility, Opportunity (MAO) Score

	0	1	2
Mobility (how freely can the person move around in their community?)	House-bound	limited access to surrounding area (needs accompaniment)	good access to surrounding area, relatively independent
Access (to what extent can the person participate in social life of the community?)	no significant social participation	limited social participation	social participation consistent (few reported obstacles)
Opportunity (to what extent does the person benefit from access to work or education?)	no access to viable work/education	access to work, not viable income OR access to education but not beneficial	access to work with viable income OR access to education which is beneficial

Results: analysis of the baseline characteristics of the beneficiaries receiving rehabilitation through the mainstream CBR project identified 25 households where the primary beneficiary was a person affected by leprosy and 568 households where the primary beneficiary was a person with disability from any other cause. This is consistent with a national finding that persons affected by leprosy constitute around 3-5% of all persons with disabilities. Analysis of the baseline characteristics demonstrated that baseline Economic Vulnerability Scores were significantly lower for households with a leprosy-affected person. However, mean baseline MAO scores were lower for non-leprosy than leprosy affected, and intriguingly, although stigma is thought to be higher for leprosy affected persons, average scores for community participation (CPI) were lower for non-leprosy than leprosy affected persons. Analysis of rates of different types of interventions did not demonstrate any significant differences between the groups in

terms of type, rate or cost of interventions. In terms of outcomes, post-intervention improvements to EVS scores were significantly higher amongst households with leprosy affected beneficiaries, and mean increases in MAO scores after intervention were higher for leprosy affected beneficiaries than non-leprosy affected. Mean increases in Community Participation Index did not differ between leprosy and non-leprosy affected beneficiaries

Table 1: Summary of baseline and post-intervention scores for leprosy and non-leprosy affected persons with disabilities

	Leprosy affected (n=25)	Other disability (n=568)	Difference (significance)
Baseline EVS	-2.89	-1.10	1.79 ($p<0.01$)
Average increase in EVS from baseline after intervention	0.33	0.1	0.2 ($p<0.01$)
Baseline MAO	3.76	2.93	0.83 ($p<0.05$)
Average increase in MOA from baseline after intervention	0.24	0.19	0.05 ($p<0.1$)
Baseline CPI	-1.12	-1.51	0.39 ($p<0.05$)
Average increase in CPI from baseline after intervention	1.25	1.24	0.01 (NS)

In terms of cost-effectiveness, the leprosy-specific project delivered a basket of interventions, including medical rehabilitation, housing, micro-credit and livelihood assistance to 250 beneficiary households of a leprosy-affected village, resulting in 19% increase in EVS scores from baseline at 1 year at a mean beneficiary cost of $400.8 per beneficiary household. The mainstream project delivered a basket of similar interventions to a mixed population at a rate of $210 per beneficiary household, resulting in an 11% increase in EVS scores from baseline at 1 year at a for leprosy affected beneficiary. This translates to $21 per % gain in mean EVS scores for leprosy specific projects, and $19 per % gain in EVS scores for general projects.

Conclusion: this analysis of field data demonstrates the relative effectiveness of including people affected by leprosy within mainstreamed CBR programmes, demonstrating at least that people affected by leprosy are not discriminated by being included in mainstreamed programmes, and that such programmes can effectively deliver benefits with similar or superior cost-effectiveness that leprosy-specific programmes. The relatively small sample size of leprosy

affected persons may limit the representativeness of the study; however, statistical significance was demonstrated for all significant findings. The relatively lower baseline EVS scores for households with leprosy affected persons may account for the relatively high rates of increase, as those with lower baselines tend to benefit more from primary interventions. Comparisons of leprosy-specific and mainstreamed programmes may include other factors influencing cost-effectiveness, such as differences in delivery model and in population characteristics.

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[1] Braithwaite J, Mont D. Disability and poverty: a survey of World Bank poverty assessments and implications. ALTER – European Journal of Disability Research / Revue Européenne de Recherchesur le Handicap, 2009, **3:** 219–232

[2] Lockwood DJ. Commentary: leprosy and poverty. *Int J Epidemiol* 2004; **33:** 269-270.

[3] WHO (2009) Enhanced global strategy for further reducing the leprosy burden due to leprosy (Plan Period 2011-2015). WHO Regional Office for SEA

[4] http://www.who.int/disabilities/cbr/guidelines/en/index.html

[5] Van Brackel W (2007) Disability and Leprosy: The Way Forward. Annals of Academy of Medicine. 36 (1)