Lessons from the evolution of a CBR programme for people affected by leprosy in Northern Nigeria

BASSEY EBENSO*, MICHAEL IDAH**, TERVER ANYOR*** & FEMI OPAKUNMI***
*School of Sociology & Social Policy, University of Leeds, Leeds, LS2 9JT, UK
**Netherlands Leprosy Relief, 75 Rayfield Road, P O Box 759, Bukuru, Plateau State, Nigeria
***The Leprosy Mission-Nigeria, 1 Ladi Kwali Road, P. M. B. 179, Minna, Niger State, Nigeria

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Summary
Objective: This paper reviews the 13-year evolution of the social economic activities in Northern Nigeria from a welfare-oriented to a community-centred programme for people affected by leprosy.
Design: The review relied on the analysis of policy and strategy documents, programme guidelines and statistical and evaluation reports.
Results: Findings revealed that the transformation among other things, demanded formulation of new programme policies and guidelines; and staff training in CBR principles and practice. Findings also showed that adopting CBR principles and community development projects can stimulate improvements in living conditions, self-esteem and acceptance of people affected by leprosy into the community. Regardless of becoming a more inclusive and participatory programme wherein people affected by leprosy contribute to programme implementation and evaluation; groups affected by leprosy remain economically dependent on the programme and partnership mobilisation is weak. This explains why the priorities for sustaining the processes and impacts generated through CBR in northern Nigeria include: i) empowering groups to access mainline services; ii) working through partners to implement CBR and attract extra funding/ownership of interventions, and iii) promoting human rights of people affected by leprosy and working for a barrier free environment.
Conclusions: In the absence of an agreeable understanding and method of assessing sustainability in CBR, we recommend the field-testing of a proposal for evaluating sustainability, to determine its utility in different contexts. Such field-tests have the potential of influencing policy and practice in the future.

Correspondence to: Bassey Ebenso, School of Sociology & Social Policy, University of Leeds, Leeds LS2 9JT, UK (e-mail: hss4bee@leeds.ac.uk)
Introduction

Leprosy is increasingly accepted as a medico-social problem rather than just an infectious disease\(^1\) that causes impairments. Though available statistics reveal a huge reduction in the prevalence of leprosy with almost 15 million people diagnosed and cured with multidrug therapy between 1985 and 2008,\(^2\) yet the social dimensions of leprosy namely stigma, poverty, public aversion of visible impairments, loss of self-esteem and dignity, remain significant challenges that need to be overcome.\(^1,3,4\) It is for the purpose of minimising social and psychological problems associated with leprosy that community based rehabilitation (CBR) programmes are established in several leprosy endemic countries across the world. Following the request for articles for the Special Issue of *Leprosy Review* on Sustainability,\(^10\) this paper reports a 13-year evolution of socio-economic rehabilitation (SER) projects aimed at people affected by leprosy in Northern Nigeria. This evolution included adoption of certain elements of the CBR approach in the past 7 years. The paper commences by providing a definition and the tenets of the CBR strategy. This is followed by a discussion of different meanings of sustainability in CBR approach, which leads to the identification of characteristics/elements for evaluating sustainability. The paper then presents milestones of the gradual transformation of eight SER projects into a coordinated CBR programme in northern Nigeria. It concludes with an assessment of sustainability of the programme and lessons learned from the evolution process.

**Definition and Tenets of CBR**

CBR was first promoted in the mid-1970s by WHO to address the shortage of rehabilitation assistance by providing people with disabilities access to services in their communities using local resources.\(^5\) A revised Joint Position Paper issued in 2004 by WHO, ILO & UNESCO defines CBR as a strategy within general community development for the rehabilitation, equalisation of opportunities, poverty-reduction and social inclusion of all people with disabilities.\(^6\) The Joint Position Paper 2004 draws attention to: i) the evolving concepts of disability and rehabilitation, ii) emphasis placed on human rights and action to address inequalities and alleviate poverty, and iii) expanding role of disabled people’s organisations (DPOs) in CBR. Moreover, the Joint Paper identifies CBR as a multisectoral strategy for improving the lives of people with disabilities and promoting the development of the communities where they live.\(^7\) CBR is implemented in over 90 countries through collaborative efforts of people with disabilities, their families, DPOs and communities; and governmental agencies and non-governmental organizations (NGOs).\(^6\) The two major objectives of CBR consist of i) maximising the physical and mental abilities of people with disabilities to accessing regular services and opportunities that assist them to actively contribute to their own communities; and ii) promotion and protection of the human rights of people with disabilities by communities.\(^5\)

In order to build a bridge from CBR policy to practice, WHO initiated the process of developing a CBR Guidelines in close collaboration with key stakeholders.\(^7\) The new guidelines aim to: i) provide a framework for the implementation of CBR, ii) highlight best practice in the field, and iii) ensure CBR is an effective multi-sectoral strategy. The new guidelines were launched in October 2010, during the 4th CBR Africa conference in Abuja, Nigeria.\(^8,9\)
DIFFERENT MEANINGS OF SUSTAINABILITY IN CBR

There are different ways of understanding sustainability. First, sustainability is understood as the continuity of change process(es) initiated through the CBR programme, in the lives of disabled people, their families and communities. This may be seen through lasting changes: i) in attitudes and behaviours towards disabled people e.g. acceptance of children affected by leprosy in regular local schools even after the termination of CBR programme; ii) within the community related to e.g. continuity of water supply, co-operatives and self-help groups started under a CBR programme; or iii) continuation of the relationship between people affected by leprosy and CBR workers after formal termination of CBR service. Notice the focus here is on maintaining an idea/relationship or the functioning/impact of something.

Sustainability can also be assessed in terms of mobilisation and participation of disabled people or their communities in a CBR programme as well as community ownership of an intervention. The focus is on participation of disabled people/community members as decision makers on CBR committees and as beneficiaries and owners of CBR services.

Thirdly, sustainability can be perceived as the continuity of CBR activities after external input of resources is stopped. This could imply continuing service delivery either to existing clients or to newly disabled people. Looked at in this way, many CBR programmes will be unsustainable especially if governments and NGOs withdrew funding for remuneration of CBR workers and resources for identifying and training CBR workers, supervising their work etc. However, if ‘continuity of activities’ is recognised as inter-connected to and dependent on building ‘stable stakeholder partnerships’ with organisations and programmes that help CBR programmes to fulfil their objectives, then it becomes even more significant to invest in networks and organisations that operate in the same domain as the CBR programme rather than pursuing continuity of CBR activities as an end in itself. Potential spin-offs of stable partnerships include shared ownership of interventions, and injection of development ideas and resources into CBR programmes. The focus here is on maintaining service delivery.

Lastly, sustainability can be inaccurately defined as financial ability of an implementing agency to maintain its structure and personnel. From this perspective, a CBR programme may be forced into changing its goals midway through their implementation if an implementing agency fails to obtain funds to sustain its operations. For instance, the CBR programme may change into a HIV control programme if it is easier to obtain funds for the latter. The focus here is on implementing agencies maintaining themselves regardless of losing sight of their original visions. This perspective denotes sustainability in the organisational context, which is outside the scope of the present paper.

The foregoing suggests a lack of agreement among planners and professionals regarding the understanding of sustainability in CBR. We propose that in the context of people affected by leprosy, sustainability is dependent on the first three of the aforementioned conceptions of sustainability namely:

(i) Ability of communities to maintain change processes initiated through CBR programmes e.g. continuity of an idea or impact of a scheme and continuity of a relationship.
(ii) Participation of disabled people/communities in decision making, evaluation and/or ownership of CBR interventions and
(iii) Mobilisation of multisectoral partnerships as a pathway to achieving continuity of CBR services.
The argument regarding the elements of sustainability will be further developed in the concluding section of this paper, where these elements will be employed to assess the sustainability of the programme in northern Nigeria. In the meantime, we challenge the perception of sustainability as ability of CBR programmes to meet their running costs or expenses as this is impractical to achieve. Neither do we view sustainability from the organisational context.

**GENERAL BACKGROUND OF THE PROGRAMME**

The CBR programme described in this paper is situated predominantly in northern Nigeria. The programme covers eight states namely: Kebbi, Sokoto and Zamfara in the northwest; Kogi, Kwara, Niger states and the Federal Capital Territory in the north central region; and Akwa Ibom state in the southeast of Nigeria. The combined 2009 population of these states is 26.7 million people, projected from 2006 census using a growth rate of 2% per annum. Compared to national socio-economic conditions in 2009, the inhabitants of northern Nigeria are more likely to be unemployed (13% vs. 5%), uneducated (48% vs. 26%), rural farmers (80% vs. 70%) and have a lower household income (GDP per capita US$ 300 vs. US$ 2,400).

In 1991 the Government of Nigeria established a country-wide leprosy control programme, called the National Tuberculosis and Leprosy Control Programme (NTBLCP) aimed at reducing the national prevalence of leprosy to a level where it was no longer considered a public health problem. The NTBLCP collaborated with four international anti-leprosy (ILEP) organisations to achieve its goal of reducing the disease burden to 1 case per 10,000 population by the year 2000. The Leprosy Mission (TLM) was subsequently contracted by NTBLCP to fund control activities in the eight aforementioned states. Interventions funded by TLM included case detection and treatment with multidrug therapy (MDT); prevention of disabilities; and socio-economic rehabilitation (SER)—as it was called at the time. This paper focuses on the SER interventions only. TLM commenced funding SER interventions in leprosy settlements in northern Nigeria in 1997. Prior to 1997, the emphasis of TLM’s work was case detection; expansion of coverage of field chemotherapy for leprosy and disability control. Following the achievement of 100% geographical coverage with MDT in 1997, the focus of TLM’s work broadened to incorporate SER of people affected by leprosy.

**Methods**

This is a 13-year historical review of transformation of the SER projects in northern Nigeria into a coordinated CBR programme for people affected by leprosy. The review relied on documentary analysis of planning, policy, and strategy documents as well as programme guidelines, statistical and evaluation reports. The subsequent paragraphs describe milestones in the three phases of evolution of the programme namely: the foundational phase (1997–2001); growth phase (2002–2007); and an ongoing maturation phase (2008 to date).

**DEFINITION AND STANDARDISATION OF TERMS**

**Community based Rehabilitation (CBR)**

CBR denotes activities and interventions implemented for the rehabilitation, equalization of opportunities, poverty-reduction and social inclusion of people affected by leprosy within
their communities. The participation of individuals affected by leprosy and their communities constitute a guiding principle for planning and implementation of CBR activities. Additional to participation, five other guiding principles of CBR are Inclusion, Self-advocacy, Empowerment, Sustainability and a Barrier-free environment.

**Socioeconomic Rehabilitation (SER)**

SER denotes activities and interventions that specifically address social and economic rehabilitation of individuals affected by leprosy, often implemented without recourse to the participation of people affected or their communities.

To minimise ambiguities arising from the use of above terminologies, the programme described in this paper is hereafter called the CBR programme. The first 5 years of evolution of the programme (1997–2001) will be referred to as pre-CBR years, and subsequent years (2002 to date) that saw progressive adoption of CBR principles are called CBR years. This standardisation excludes references to existing programme documents that carry the title e.g. reports, policy and strategy documents which were produced in pre-CBR years.

**MILESTONES IN THE EVOLUTION OF THE PROGRAMME**

To facilitate the visualisation of the historical process described below, Figure 1 summarises characteristics and milestones of each phase of evolution and the main outcomes that can be related back to specific changes during the process.

<table>
<thead>
<tr>
<th>Pre-CBR years (1997–2001)</th>
<th>Key outcomes related back to specific changes</th>
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<tbody>
<tr>
<td>Characteristics or Milestone(s)</td>
<td>i) Non-existence of CBR policy in first 4 years of services ii) Mainly addressed social and economic problems of individuals iii) Strategic planning for stakeholders of CBR held in the 5th year</td>
</tr>
<tr>
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<td>i) Organisational policies formulated in the 5th year ii) CBR field guidelines implemented from 5th year</td>
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<tr>
<th>Growth phase (2002–2007)</th>
<th>Key outcomes related back to specific changes</th>
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<tr>
<td>Characteristics or Milestone(s)</td>
<td>Key outcomes related back to specific changes</td>
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<tr>
<td>i) Evolved from individual-focused to group-focused programme ii) Adoption of principles of participation and self-advocacy iii) Capacity building of staff in CBR principles</td>
<td>i) Community projects stimulate inclusion &amp; stigma-reduction ii) IDEA-Nigeria established in December 2003 iii) Local chapters of IDEA formed in several states in Nigeria</td>
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<tr>
<th>Ongoing maturation phase (2008 to date)</th>
<th>Key outcomes related back to specific changes</th>
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<tr>
<td>Characteristics or Milestone(s)</td>
<td>Key outcomes related back to specific changes</td>
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<tr>
<td>i) Promotion and empowerment of self-help groups ii) Mobilization of partnerships with NGOs and governments iii) Promotion of cross-disability CBR programme</td>
<td>i) No of groups &amp; group members doubles compared to '07 ii) No of groups attaining autonomy also doubles iii) Partnerships lead to shared-funding/ownership of projects</td>
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**Figure 1.** Showing milestones & key outcomes in the evolution of the CBR programme in Northern Nigeria.
The pre-CBR years of the programme consisted of small beginnings and gradual expansion of coverage to five of the eight TLM-assisted states. This period was characterised by a lack of organisational policy for CBR; adoption of different objectives and interventions; and a pace of development that varied in each state. In general, state projects addressed social and economic problems of individuals without consideration for family or community needs. Typical individual interventions consisted of: i) micro-credit loans, ii) vocational training, iii) housing projects for the homeless, and iv) welfare payments and distribution of ‘food packets’ to people with severe impairment who were unable to work.

A formal evaluation of pre-CBR years conducted in April 2002 corroborated the individual-focus and welfare-oriented nature of projects in the five states. The evaluation thus recommended: i) adoption of CBR philosophy necessitating the participation of people affected by leprosy/communities in planning and implementation of services; ii) training of staff in CBR principles; iii) improvements in loan-recovery efforts; and iv) standardisation of recording/reporting to facilitate the monitoring of progress of activities and objectives.

A turning point in the life of the programme occurred in April 2001, when TLM convened a meeting of stakeholders to deliberate the strategic directions of the programme. Stakeholders at the strategic planning meeting included CBR workers; representatives of people affected by leprosy/communities; and representatives of government and development agencies. The outputs of the meeting comprised: i) Strategies for SER 21 for the period 2002–2006; and ii) Guidelines for implementation of SER.22 The documents followed stakeholder acknowledgment of the need to address problems of stigmatization, psychological deprivation and low quality of life experienced by people affected by leprosy in the region. The strategic objectives adopted for subsequent five years (2002–2006) consisted of:

- Economic empowerment to enhance productivity of people affected by leprosy.
- Restoration of social status and improvement of quality of life of individuals through appropriate interventions.
- Restoration of dignity through active participation of people and families affected by leprosy in their communities.
- Promotion of acceptance and inclusion of people affected by leprosy.
- Advocacy and collaboration with relevant governmental agencies and NGOs to facilitate access of communities affected by leprosy to basic amenities and infrastructure.

The following activities were adopted to achieve the strategic objectives:

- Case-by-case assessment of social and economic status and needs of potential beneficiaries.
- Formulation of CBR plans in partnership with CBR committees that include representatives of beneficiaries.
- Addressing identified needs via diverse CBR interventions.

These activities were implemented in the context of integrated LCP involving physiotherapists, doctors, nurses, LCP supervisors and other paramedical staff.
GROWTH PHASE (2002–2007)

a) Community-focused Interventions & Participation

The transformation of the programme during this phase necessitated a shift in focus from ‘individual-centred’ to ‘community-focused’ interventions. This demanded training of CBR workers and geographical expansion of CBR services to all eight TLM-assisted states. Interventions implemented during the growth phase comprised community development projects e.g. provision of electricity, wells and water pumps; construction of schools and provision of scholarships; and promotion of livelihoods through micro-credit loans, self-employment and vocational training. The success of community development interventions depends on a great deal of planning and participation of people and communities affected by leprosy.

b) Self-advocacy

Another defining moment for the programme was the launch (in December 2003) of the Nigeria chapter of the International Association for Integration, Dignity and Economic Advancement (IDEA).23 The founding of IDEA-Nigeria heralded the participation of DPOs in CBR activities in northern Nigeria. The launch of IDEA-Nigeria is integral to IDEA’s global advocacy campaign of eliminating leprosy-related stigma initiated in March 2003.24 IDEA-Nigeria raises awareness about the rights of people affected by leprosy, and collaborates with partners to promote access to services and opportunities. The self-advocacy campaigns have resulted in establishment of local chapters in a majority of Nigeria’s 37 states.

An evaluation28 of the programme conducted in 2008 by a four-member team which included two disabled people, made three principal observations and recommendations. First, livelihood interventions—self-employment, self-help groups and micro-credit loans—were applauded for improving the living standards and self-confidence of a majority of people affected by leprosy. Regardless of these improvements, the evaluation recommended the centrality of group empowerment to furthering the chances of people affected by leprosy accessing resources from mainline poverty alleviation programmes or financial institutions.

Secondly, the programme was praised for contributing to stigma-reduction and community inclusion through interventions that catalysed the general public to relocating to the vicinity of leprosy settlements. Interventions that attract non-disabled residents to leprosy settlements include provision of water supply and electricity, construction of schools and clinics, community halls etc.

Thirdly, whereas the programme was applauded for stimulating participation of people affected by leprosy and communities in programme planning and implementation, it was criticised for being a single-disability and donor-dependent programme. It was thus advised to broaden its participant base to include people with other disabilities while forging partnerships with government agencies and NGOs as a means to increasing funding/ownership of interventions.

ONGOING MATURATION PHASE (2008 TO DATE)

Further to promoting inclusion, self-advocacy and participation of people affected by leprosy during the growth phase, the programme has adopted two additional principles beginning
from 2008. These are empowerment of self-help groups to access mainline resources and mobilisation of stable partnerships explained below:

\[ \text{Empowerment of groups for autonomy and access mainline resources} \]

At least 15 of 29 self-help groups in the programme were assisted to register with government ministries as cooperatives/development groups. See Table 1 for a trend of self-help groups between 2007 and 2009.

The 15 groups currently manage their own affairs with minimal supervision of the programme. For instance, they organise regular meetings to make savings, track repayment of loans and keep their own records. One such cooperative group (in Kebbi state) accessed a loan of US$4,000 in 2008, from a Micro-Finance Institution and a further US$11,000 in 2010 after successfully reimbursing the previous loan.

\[ \text{Partnership building with government agencies} \]

The prime target of this partnership drive is the Ministry of Women Affairs & Social Development – the lead government department for disability issues. Other agencies include Ministries of Agriculture, Education and Ministry of Water Resources. The outcome measures for this partnership drive include: i) government funding of CBR, and ii) access of communities affected by leprosy to government poverty-alleviation projects. This mobilisation process is at different stages in the eight states supervised by the programme. For instance, Sokoto State is an example of full government participation evidenced by the funding of the leprosy referral centre and the CBR programme. This level of partnership was achieved through the resolve of government officials to transform living conditions in leprosy communities.

\[ \text{Partnership building with NGOs in the domain of disability} \]

A dimension of this partnership is achieved through TLM’s membership of country-level networks. An example of country-level partnership is TLM’s growing partnership with CBM-International evidenced by: i) joint-funding of a cross-disability project in Kogi state; ii) shared expertise for CBR trainings; and iii) shared expertise for programme evaluations. A second dimension of NGO partnerships is achieved through CBR workers forging partnerships at the state level. Efforts in this direction have resulted in improved community

\[ \text{Table 1. Breakdown of livelihoods data by year 2007–2009*} \]

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<tr>
<th></th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
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<tbody>
<tr>
<td>Vocational Training</td>
<td>27</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Loans for Self-employment or income generation</td>
<td>521</td>
<td>840</td>
<td>757</td>
</tr>
<tr>
<td>No of Self-help groups in programme</td>
<td>17</td>
<td>30</td>
<td>29</td>
</tr>
<tr>
<td>Total members of self-help groups</td>
<td>346</td>
<td>471</td>
<td>982</td>
</tr>
<tr>
<td>Average members per group</td>
<td>20</td>
<td>16</td>
<td>34</td>
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*Source: Annual statistical reports of TLM International. 25–27
access to mainstream resources e.g. from commercial banks, UNDP and World Bank poverty-alleviation project in Kebbi, Kogi and Kwara states respectively.

Regarding statistical evidence of CBR activities, Figure 2 provides a general trend of CBR beneficiaries (from 2002–2009).

The figure depicts an increasing trend in livelihood and education beneficiaries and a corresponding but gradual reduction in welfare-type interventions beginning from 2006. Notice the abrupt decline in education beneficiaries from 722 in 2008 to 367 in 2009 that reflects increased government & family funding of education in 2009.

Furthermore, Table 1 shows an increase in self-help groups and members joining these groups from 2007–2009 which are outcomes of the promotion of self-help groups from 2007. It is reasonable to highlight that the increase in livelihood figures conceal a diminishing interest in vocational training in the region (See Table 1). We speculate that the overarching poverty in northern Nigeria is instigating a preference for self-employment, self-help groups and micro-credit which provide direct financial reward for solving family needs compared to vocational or skills training that require a preliminary period of investment in some apprenticeship before they can earn some future income.

**Discussion**

This paper traced the gradual transformation of a CBR programme for people affected by leprosy in northern Nigeria, identifying three phases in its 13-year journey—pre-CBR years, the growth phase and an ongoing maturation phase. While the pre-CBR years were largely characterised by the non-existence of organisational strategy for CBR with state projects arbitrarily addressing social and economic problems of individuals; the growth phase

![Figure 2. CBR Beneficiaries by Type of Intervention 2002–2009.](image)
heralded a progression from welfare-focused to more community-focused programme. The programme can be credited for partnering with NGOs and government agencies to adopt four of the CBR principles during its growth and ongoing maturation phases. These are inclusion, participation, self-advocacy and empowerment of groups. Notwithstanding the principles are adopted, the critical question should be whether the processes generated through CBR interventions or their impacts on individuals/communities are sustainable. We believe the extent of sustainability of interventions, processes and their impacts influences success at addressing the social problems of leprosy and lifting people out of poverty. Before answering the question regarding the sustainability of the programme in northern Nigeria, we note that CBR by its very definition consists of various interventions i.e. rehabilitation, equalisation of opportunities, poverty-reduction and inclusion of disabled people into the community. As CBR is not a discrete intervention, its expected outcomes are difficult to standardise, making CBR effectiveness/success hard to establish.30

The problem is further compounded by the absence of an agreeable meaning of sustainability in the CBR approach. In spite of these dilemmas, we propose sustainability should be regarded as a process on a continuum rather than the outcome of an intervention(s). This proposal arises from the conviction that sustainability is interconnected with and depends on four other processes viz:

(i) Participation of disabled people/communities in decision making, ownership and evaluation of CBR programmes.
(ii) Continuity of change processes initiated through CBR interventions and their impact on individuals and communities.
(iii) Empowerment of groups to access mainstream resources and services.
(iv) Stable networks and partnerships with NGOs and government agencies.

If sustainability is understood as a process, it is possible to describe changes in sustainability by appraising the situation along the continuum. Drawing inspiration from Rifkin & Kangere’s work on community participation (2002),31 we propose changes in sustainability can be assessed by describing the situation along four continuums of the above factors/elements necessary for sustainability. Viewed in this way, our assessment of the sustainability of the programme in northern Nigeria is as follows:

PARTICIPATION OF DISABLED PEOPLE AND COMMUNITIES

The transition from an individual-focused and non-participatory programme to one in which people affected by leprosy currently participate in planning, implementation and evaluation in 2008 is a testament towards sustainability of the programme. An example of such participation is Zamfara state where the CBR worker is someone affected by leprosy. Although the programme endorses evaluation teams that include people affected by leprosy, nonetheless, an independent evaluation conducted by people affected by leprosy or community members is far from realisation.

CONTINUITY OF CHANGE PROCESSES OR THEIR IMPACT

We regard the continuing behavioural change towards people affected by leprosy demonstrated by relocation of non-disabled people to live in vicinity leprosy settlements
as a mark of progress towards sustainability. Furthermore, the autonomy of 50% self-help groups is also indicative of progress towards the sustainability of such schemes. We believe an incentive for striving towards autonomy is group members’ recognition that self-help groups constitute their lifeline to stable livelihoods and a pathway to economic self-reliance.

EMPOWERMENT OF GROUPS TO ACCESS RESOURCES

Whilst the CBR programme has been successful in knowledge transfer and stimulation of self-help groups, it has been less successful at empowering groups to accessing financial services on their own. This is partly due our lack of expertise in this area. A lot needs to be done here.

MOBILISATION OF STABLE PARTNERSHIPS

Similar to group empowerment, our efforts at forming stable partnerships are at an early stage. While partnerships with a few NGOs and government agencies have resulted in shared funding and ownership of CBR projects, our chances of achieving sustainability in this area is still remote.

Having attempted to summarise the degree of sustainability of the programme, the paragraphs below provide lessons learned from the evolution process.

FACILITATORS OF THE PROCESS

In hindsight, the process in northern Nigeria was facilitated by three factors. First, TLM’s congenial disposition was the most significant facilitator of the process. This organizational disposition is summed up in a pledge “To minister...to the physical, mental, social and spiritual problems of individual and communities disadvantaged by leprosy and working with them to uphold dignity and eradicate leprosy.” This declaration aided policy/administrative support for the transformation of the CBR programme. Secondly, TLM’s support for the process fed into a universal commitment (by WHO, ILEP and governments) to solving social problems of leprosy particularly impelled by a rapidly declining global prevalence in the late 1990s. Lastly, a positive networking atmosphere and mutual trust among disability NGOs in Nigeria aided TLM’s ongoing partnership with CBM in CBR trainings and joint funding and evaluation of projects.

What were the key points in the learning process? And what are the priorities for the ongoing CBR work in Nigeria?

KEY POINTS IN LEARNING PROCESS

1. Role of CBR workers: Experience during pre-CBR years showed that using medical staff (doctors, nurses, physiotherapists etc) as CBR workers sometimes promoted less participatory practices. This is partly due to the inherent nature of medical trainings and how medical staffs relate to clients and communities. This slight hesitancy with implementation of participatory approaches was enhanced via regular consultation/dialogue, training in CBR principles & recruiting non-medical workers to manage new CBR projects.
2. **Programme policies and guidelines:** As programmes expand and mobilise additional resources, it is essential to consolidate their successes through formalising organisational procedures, programme policies and guidelines that provide direction to and stabilise programme operations.

3. **Will people affected by leprosy always need CBR support?** It is often said that people affected by leprosy will always remain dependent on CBR programmes. Our experience is that: given the right participatory atmosphere, people and groups affected by leprosy can attain autonomy i.e. do not depend on CBR programmes for regular financial needs. We believe in ongoing contact with the programme for empowerment until groups become financially self-reliant i.e. able to access finances/services from mainline institutions. This will take time.

4. **Transformation of CBR programmes take time:** This is because it takes time to win the trust of communities and to implement participatory approaches. But once trust is developed, communities are often willing to participate in helping to change the lives of people with disability.

5. **Partnerships are vital for success:** No organisation/government working alone can alleviate the social needs of people affected by leprosy. Partnerships provide opportunities for sharing information on services; reducing duplication and assessing new ways of responding to social needs.

6. **Evaluating Success at addressing social problems of leprosy:** This should be evaluated both by the extent of adoption of CBR principles and the continuity of processes generated through CBR interventions or their impact on individuals and communities.

**KEY PRIORITIES FOR ONGOING CBR WORK IN NIGERIA ARE:**

1. Working through partners/communities to implement CBR.
2. Inclusive CBR services incorporating people with diverse disabilities.
3. Promoting the human rights of people affected by leprosy and working for a barrier free environment.
4. Empowering groups to access mainline resources and services.

**Conclusion**

It is hoped that the lessons from the evolution of the programme in northern Nigeria will inspire implementation/ management of CBR for people affected by leprosy in other settings. It is clear from the foregoing that adopting CBR principles and community development interventions are valuable for stimulating improvements in living conditions, self-esteem and inclusion of people affected by leprosy into the community. Regardless of becoming a more inclusive and participatory programme wherein people affected by leprosy contribute to programme implementation and evaluation, a lot remains to be done in the areas of group empowerment and mobilisation of stable partnerships. This explains the programme’s ongoing priorities of: i) working through partners and communities to implement CBR, ii) enabling self-help groups to access mainline services; and iii) promoting human rights and working for a barrier-free environment for people affected by leprosy. We recommend the field-testing of our proposal regarding meaning and evaluation of sustainability in CBR,
to determine their utility in different contexts. Such tests have the potential of influencing policy and standardising future practice.

Acknowledgements

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