Responding to the challenge of leprosy-related disability and ultra-poverty

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Summary

Introduction: The Millennium Development Goals have provided much needed attention to extreme poverty reduction. However, people with disabilities are disproportionately affected by poverty and in some countries, even the goal of US$1 per day is far out of reach. For people with leprosy-related disability living in ultra-poverty (on less than 50 cents a day), many mainstream poverty reduction strategies are inaccessible and inappropriate.

Method: A project in north-west Bangladesh developed a more contextually meaningful definition of ultra-poverty according to nutrition energy intake. A total of 2372 people with leprosy-related disability were surveyed. Of those, 1285 individuals fell below the ultra-poverty line. Individualised interventions were implemented over an extended period of time, comprised of targeted practical assistance, enhancing community links, advocacy for entitlements, and further linking with other initiatives.

Results: Follow-up data available for 856 individuals showed an average increase in per capita income of 83%. Personal contribution to the family income increased by 65%. There was a 51% increase in families having access to a latrine. Finally families reported eating 30% more meals per day, up from an average of two meals per day.

Conclusions: The initiative sought to address poverty in a wide variety of ways, using minimal inputs. Over several years, the results indicate a significant change in the economic situation of individuals with leprosy related disabilities. Other organisations are encouraged to duplicate the intervention and share their results.

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Introduction

The first and arguably the most fundamental of the (soon to be reviewed) Millennium Development Goals is to ‘eradicate extreme poverty and hunger.’ The initial indicators for this goal were: to achieve full and productive employment and decent work for all; to halve the proportion of people who suffer from hunger; and to halve the proportion of people whose income is less than US$1 a day, within 25 years.1

While achievement of the goals has been mixed due to a number of factors,2 it is clear that poverty and disability are closely related, and that achievement of the goals is linked with progress in addressing disability-related concerns.3 People with disabilities (and their families) are more likely than the rest of the population to live in poverty; disability adds to the risk of poverty, and conditions of poverty increase the risk of disability.3 People in extreme poverty as well as those with a disability lack adequate access to education, health care facilities and employment, and both groups experience stigma and discrimination.4 In terms of population, while people with disabilities make up 10% of the world’s population, they make up 20% of the world’s poor people.3 Indeed, the United Nations definition of poverty strikes a chord with many of the issues and concerns in the disability and development area. This definition states:

‘Fundamentally, poverty is a denial of choices and opportunities, a violation of human dignity. It means lack of basic capacity to participate effectively in society. It means not having enough to feed and clothe a family, not having a school or clinic to go to, not having the land on which to grow one’s food or a job to earn one’s living, not having access to credit. It means insecurity, powerlessness and exclusion of individuals, households and communities. It means susceptibility to violence, and it often implies living in marginal or fragile environments, without access to clean water or sanitation.’5

Recognising the strength of the connection between poverty and disability, we identify a specific and extreme case, ultra-poverty, describing a programme developed to address ultra-poverty and disability in the context of leprosy. We then draw implications for community-based rehabilitation (CBR) and inclusive development (ID).

ULTRA-POVERTY

Despite the severity of the $1 per day measure, it is clear that in some very poor countries such as Bangladesh, even this measure is too insensitive to differentiate between extremely poor community members, and the poorest.6 As a result, the term and definitions of ‘ultra-poor’ have been used to identify those people who have the lowest levels of food security and are the most vulnerable.

Ultra-poverty is manifest in a complex and pernicious interaction between income, basic necessities, food intake, health and wellbeing. People living in ultra-poverty generally have less access to: services, health care, education, sanitation, and clean water. It is characterised by the vicious cycle of chronic food insecurity, and no asset base to deal with inevitable disruptions in income (due to adversity, market sale price variations, market purchase price variations, local disasters, crop failure, etc.).

Ultra-poverty pertains to being amongst the poorest of the poor in low-income countries. Related to the common definition of extreme poverty, it has been defined as living on less than 50 cents per day.7
A DISABILITY SERVICE CONTEXT

Over a number of years, in The Leprosy Mission, Bangladesh, there has been an ongoing struggle to define and appropriately respond to poverty. Thousands of known beneficiaries are very poor, and many interventions have been tried over the years to address both poverty and disability concerns. Initially, the assistance was in the form of welfare or relief assistance handouts provided to those apparently in crisis. Later, vocational training, educational support, and assistance with the provision of clean water and sanitation were added, but appropriate targeting of services remained a challenge. Over time, the primary method of intervention was shifted to a group-based CBR approach, with savings and a form of micro-credit offered. It became evident, however, that some of the neediest beneficiaries were still not being reached and that these interventions were sometimes ineffective in the case of the poorest, and specifically in the case of some disabled people who were ‘ultra-poor’. The extent of their poverty, their isolation from the community, and the immediacy of their needs, was such that they appeared unable to benefit from microfinance and other CBR interventions.

MICRO-FINANCE AND ULTRA-POVERTY

This observation from practice is consistent with published research from Uganda which has found that for micro-finance, access patterns of people with disabilities reflect those for the non-disabled, favouring people whose lives are more stable, are economically active and have some education. In Bangladesh some types of micro-finance have been found to be unsuccessful with the ultra-poor, because they are often too poor to engage in economic activity.

In some settings there have been attempts at reconceptualising micro-finance to make it more suited to the ultra-poor (through flexible repayment schedules, consumption smoothing, production loans, as well as extension and training services). However, a recent systematic review warned against targeting the poorest of the poor with micro-finance because of the risk of being made even poorer and further indebted, suggesting that micro-credit should be targeted at those who have some level of financial security.

The combination of leprosy-related disabilities with ultra-poverty adds layers of stigma and discrimination which further impedes access to micro-credit. For example, in Bangladesh, community attitudes often equate disability with ‘inability to work’. As a result, people with disabilities are rarely offered loans and even if they join larger micro-finance groups or cooperatives, they struggle to obtain loans. It would appear that in micro-finance as in much of life, the greatest barriers to the inclusion of people with disabilities are stigma and prejudice.

CASH TRANSFERS AND ULTRA-POVERTY

Other ultra-poverty interventions have included direct food transfers with and without conditions placed on them, or direct food and cash transfers, with and without conditions. Such cash or food transfers can be conditional (subject to the households meeting certain demands, such as children attending school) or unconditional, and are often targeted (given only to households or individuals meeting particular criteria). In essence they amount to the transfer of food and/or money to people by NGOs or governments, rather than the provision of services or building of capacity.

Cash transfers have been seen as potentially contributing to the economic and food security of very poor households, improving access to health care and contributing to the self-esteem of
people with disabilities. In some instances, cash transfers have been seen as a ‘silver bullet’ to address ultra-poverty, although there are also serious questions as to the sustainability of these approaches. In deregulated markets, the use of cash transfers may lead to rising prices, inflation, and poor quality services or goods. They are also vulnerable to targeting errors and diversion from deserving recipients. Finally, cash transfers may only be useful for the ultra-poor where they are complemented by public provision of essential services.

Method

A SERVICE RESPONSE TAILORED TO ULTRA-POVERTY

In response to these concerns, The Leprosy Mission Bangladesh designed an initiative to complement a larger group-based micro-finance and savings CBR project. The CBR project provides a structure for all members to make monthly savings contributions, and earn additional capital by meeting certain development criteria. Project group members at the local level use their accumulated saved funds to make loans to group members. While the system is flexible and exists to benefit members, members are encouraged to attain their own savings goals and are expected to recover a certain percentage of their loans.

The specific ultra-poverty initiative included in this project was implemented in north-west Bangladesh, targeting people with a disability resulting from leprosy. Ultra-poverty was defined in terms of the inability to regularly access 2100 kcal (8790 kilojoules) energy consumption per person, per day. Operationally, this was defined as the market price of 583 grams of uncooked rice per person, per day. For example, a family of four would need a daily income of $1.17 in cash or in kind, based on rice at $0.50 per kg ($0.50 per kg rice × 0.583 kg rice × 4 family members = $1.17). The CBR group leaders confirmed that this threshold identified group members who were the poorest, who consistently had difficulties saving, and who were often unable to obtain a loan from the group.

Six field staff were employed in the initiative to cover an area of approximately 7000 square kilometres. They undertook an initial 2-day training programme on poverty assessment, a 2-week course in financial management, and a 10-day course on Participatory Rural Appraisal (PRA) methods. Staff then surveyed all known individuals with leprosy related disabilities within a focus region and identified those living below the ultra-poverty line. A number of indicators were collected (Table 1), with particular attention to per capita

| Table 1. Summary of poverty survey among 2372 people with leprosy related disabilities in north-west Bangladesh |
|--------------------------------------------------------|----------|----------|
| Monthly Household expenditures (USD)                  | $34.91   | $25.97   |
| Monthly Household income (USD)                         | $38.30   | $25.97   |
| Monthly Personal Income (USD)                          | $18.04   | $10.06   |
| Daily Per Capita income (USD)                          | $0.28    | $0.19    |
| Land ownership (m²)                                    | 1315 m²  | 202 m²   |
| Number of household members                            | 4.5      | 4.0      |
| Years of education                                     | 1.7      | 0.0      |
| Average number of daily meals                          | 2.2      | 2.0      |
| Number with a latrine                                  | 1357     |          |
| Number with access to clean water                      | 2316     |          |
income in the household. Of those surveyed to date \( (n = 2372) \), the average daily income of only 28 cents per person reflects the extent of poverty and contrasts with the United Nations definition of extreme poverty.

The snapshot of Table 1 indicates that on average ultra-poor survey respondents ate two meals per day (most preserving cooking fuel by cooking once). They had very little education, which substantially limited their employment options. Most were also functionally landless, which in rural Bangladesh is defined as owning less than 2000 square metres, since it is not possible to sustain an agricultural livelihood on less land in Bangladesh.

**INTERVENTION**

Based on the survey, the following intervention was provided. When a person was identified as living below the ultra-poverty line, field staff worked with them to develop a personal, aspirational plan, in cooperation with their family and community. Due to the low literacy rate, aspirational plans were visual and picture-based. The idea of the ultra-poor person ‘owning’ the individual plan was felt to be essential for long-term success of any intervention.

Planning started with a simple hand drawing to represent the individual’s physical assets (buildings, agricultural holdings, livestock, etc.), their social assets (family), and other assets (such as access to a neighbour’s field) at that point in time. They then drew a second picture to describe what position they would like to be in 3 to 5 years’ time. A planning exercise was then undertaken to identify and document steps and inputs needed (from the person, the project, the person’s family, or their community) in order to achieve that aspiration.

In addition to the strategies noted in the plan, the initiative also took in to account the need to address poverty at multiple levels. First at the individual level, some basic practical assistance was provided by the initiative without expectation of reimbursement, however it was clearly established that the assistance had definite time and resource limits. Since each plan was individual, there was considerable diversity in the types of assistance, however it was always provided in small amounts with a definite goal in mind. In some cases, the plan included short term provision of food, which would be matched with an income generating plan to provide for the future. Some families requested assistance to pay for their children’s education, as a form of future social security. Some families sought to start a small business and required capital or vocational training to run the business (budgets for capital assistance were generally limited to US$150 per family per year). Vocational training was arranged at a local community level through ‘apprenticeship’ type arrangements, rather than through formal training. To improve health, and therefore increase productivity, some families requested support to build a sanitary latrine or tube well. A small number of families caring for an elderly person with leprosy-related disabilities were offered a stipend to reduce family strain in providing community care, and to prevent long periods of hospitalisation.

Second, at a community level, the initiative sought to connect people with their communities. Community leaders were often involved in assisting with developing personal plans and sometimes contributed materially in some way. Where larger scale initiatives were required, project investment had to be matched by individual and community labour and resources.

Third, at a government level, the project sought to connect beneficiaries with government stipends and assistance wherever possible. It provided assistance to connect people with their rights and safety net provisions for which they are eligible. While Bangladesh has a tradition of government safety nets, funding has fallen from 1% of the GDP in the late 1990’s to 0.4%
of the GDP in 2005. While these government stipends are helpful, particularly in the case of ultra-poverty, it is also acknowledged that they are generally inadequate, as they are paid out irregularly and the amounts tend to be very low (US$2-$4 per month). Some basic advocacy was also provided, and there were flow-on effects from the related group-based CBR project in the same catchment area, which had significant investment into advocacy.

Finally, the initiative sought (again, within organisational constraints) to be extensive rather than intensive, seeking to progress slowly over a period of time. The long-term expectation of the project was that people in ultra-poverty would be able to live above the poverty line and connect with the CBR project in their area, and/or to join a micro-finance group. To this end, people involved in the initiative had periodic follow-up assessments to monitor progress and changes following assistance.

Results

OUTCOMES OF AN ULTRA-POVERTY SERVICE RESPONSE

Through the survey, 1285 individuals were identified as ultra-poor and approximately 1100 have received services through the initiative. Selection for the initiative was based on the family’s per capita income being below the project’s ultra-poverty line. Individuals selected had follow-up visits at least six times per year. Of those involved in the initiative, 856 have been reassessed one or more times (on an annual basis) following the implementation of their plan. The average time between initial and latest assessments was 43 months. Average baseline and latest follow-up outcomes are summarised in Table 2 for all 856 participants.

The results of the programme showed positive change. Average household income increased by 81%. Given that family size remained essentially the same, daily per capita income increased by 83%. Land ownership increased slightly, however 207 more families now have access to a latrine. The average family also reported eating more meals per day.

Discussion

A key priority for the ultra-poverty initiative was that the individuals should ‘own’ their plan. This required considerable time and resources; it often required one or two days to generate a

| Table 2. Baseline and follow-up poverty assessment, at an average of 43 months between baseline and most current follow-up, for people who had a plan implemented (n = 856) |
|-----------------------------|-------------|-------------|----------------|--------------|
|                             | Baseline    | Follow-up   | Change        | Percent Change |
| Monthly Household income (USD) | $19.67    | $35.70      | $16.03        | ↑ 81%        |
| Monthly Personal income (USD) | $9.09      | $14.96      | $5.87         | ↑ 65%        |
| Daily per capita income (USD) | $0.16      | $0.30       | $0.14         | ↑ 83%        |
| Land owned (m²)              | 319         | 339         | 20            | ↑ 06%        |
| Number with latrine          | 406         | 613         | 207           | ↑ 51%        |
| Average number of meals per day | 1.95     | 2.54        | 0.59          | ↑ 30%        |
single person’s plan. Recognising that each individual is unique, and that the circumstances of their poverty are complex, a clearly individualised and multifaceted process was developed and implemented. Previous experience with ‘one-size-fits-all’ interventions with limited options indicated that these had low levels of ‘ownership’. In such cases ‘recipients’ may see the ideas, strategies and resources as coming from the intervention and may attribute both positive and negative outcomes as intervention-related.

In the current project, the extensive variety of low-resource interventions meant that in all possible instances, field staff and people in ultra-poverty had to work with existing resources and contacts. While this was difficult due to the extreme nature and urgency of people’s circumstances, it also meant that change happened incrementally. In the current project, people in ultra-poverty slowly gained experience with their work or business, and required careful reinvestment to achieve outcomes.

The initiative outlined above acknowledged that poverty and disability are both highly complex, and ultra-poverty in the context of leprosy-related disability, particularly so. In response it has sought to complement individual interventions with community and systems-level strategies, and balance immediate response with a long term approach to building capacity and resources. The initiative tailored interventions in light of concerns that the ultra-poor are too poor to benefit from many interventions or engage in economic activity. As a minimalist and time limited approach which did not require repayment, it sought to alleviate the risk of people being made even poorer and further indebted. Such features should characterise disability and poverty interventions in developing countries.

**Conclusion**

The initiative sought as much as possible to minimise social isolation, stigma and prejudice towards the ultra-poor. It used very practical methods, involved other stakeholders in negotiations, and involved community members and leaders in building understanding and developing localised responses. As a small scale and targeted initiative, it was not subject to many of the negative dimensions of cash transfers (such as rising prices, inflation, and poor quality services or goods). Importantly, it also included a dimension of public provision and advocacy for entitlements, so is likely to have an added degree of sustainability over time. This example will have numerous implications for poverty-related interventions and particularly for CBR and inclusive development initiatives, which seek to respond to the challenge of extreme and ultra-poverty.

Finally, while these results are very encouraging, it is important to recognise that they may have also been affected by a number of other factors. At the time, other dynamics were also at work in the Bangladesh economy, such as a very gradual reduction in overall poverty. Likewise other NGOs were also working with various communities in the catchment area. Further, the initiative took place in a relatively stable agricultural environment, so while the harvest was still quite variable, widespread crop failures due to major drought or flood were not recorded. Despite these factors, the consistency and amount of change associated with the current project is noteworthy. To more clearly establish the viability of this approach, it will be important to duplicate the intervention in other areas, and other countries. It will also be very important to periodically reassess the individuals and families involved, to document whether outcomes reported to date have been sustained.
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