‘Double mainstreaming’: including people affected by leprosy in poverty reduction programmes

MIKE GRIFFITHS
Consultant/Director of Research, Social Policy & Poverty Research Group, Wingabar Lane, Bahan Township, Yangon, Republic of the Union of Myanmar

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Evidence that people with disabilities, including those affected by leprosy, are disproportionately affected by poverty is well known, and evidence points to increased rates of poverty of households with members affected by leprosy. Data from Myanmar suggest that households with a leprosy-affected member have double the rates of household poverty than households with a member who is disabled from any other cause. Rather than pursuing exclusive programmes, the integration of rehabilitation for people affected by leprosy into general disability ‘is what ultimately offers the best future for people affected by leprosy.’ However, effective poverty reduction for people affected by leprosy needs to take place in the context of broader inclusion movements. Mainstreaming of leprosy rehabilitation should be approached on the basis of human rights principles and not only in consideration of economy or efficiency. However, with the emphasis in the broader disability movement on wider ‘Disability Inclusive Development’, the requirement is not simply to ensure that leprosy-affected people are included in the disability movement, but to ensure that they are further included in the wider development agenda as part of the disability mainstreaming. This ‘double mainstreaming’ ultimately seeks to ensure that leprosy-affected people are enabled to realise their rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This approach places the responsibility for inclusion of leprosy-affected people with all stakeholders, requiring providers of healthcare services, education, livelihoods, employers, legislators, transport services, development programmes and political movements to take necessary steps to ensure full inclusion of leprosy-affected people as equal right holders. Critically, this approach rejects the notion of creating or upholding special rights or entitlements.

Correspondence to: Mike Griffiths (e-mail: drmike@psmail.net)
Evidence from Myanmar

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. From 2009, TLM Myanmar also worked in collaboration with a number of mainstream development organizations to implement inclusive early recovery, and later inclusive community development programmes directed towards poverty reduction-representing the second step in ‘double mainstreaming’. Comparisons between TLM’s programmes before and after the change of approach demonstrated that double mainstreaming enabled a fourfold increase in the number of new contacts with leprosy affected persons, with better outcomes and superior cost-effectiveness than leprosy exclusive programmes. Moreover, mainstreamed programmes involved partners and donors with little or no experience in leprosy, but for whom disability inclusion was seen as necessary as a matter of principle, and as a matter of effective poverty reduction.

However, despite policies for inclusion at central level technically mandating inclusion of Persons with Disabilities, a recent survey of humanitarian organizations in Myanmar in receipt of institutional funding revealed that only 4% of organizations could identify any activities designed to enable equal inclusion of people with disabilities. Typically, where inclusion does occur, the emphasis is on identifying and prioritising people with disabilities to be beneficiaries of the planned intervention, usually as part of a matrix of ‘vulnerable groups’ which includes women headed households and older people. Whilst laudable, this approach falls short of the equal inclusion described by the UNCRPD, which instead emphasises inclusion in all aspects of the process of humanitarian projects (and indeed other aspects of life). A process based approach to inclusion moves away from asking ‘How many beneficiaries with disabilities?’ and instead asks ‘How have we ensured equal access to this project for people with disabilities?’ This is consistent with a rights based approach for two reasons: firstly, it does not assume that all persons with disabilities are ‘vulnerable’ and therefore in need of intervention. Secondly, it assumes that people with disabilities can and should contribute to the process of the project in ways other than simply being a recipient of services or benefits. When applied at community level, this approach has been shown to increase participation of people with disabilities in community decision making, reduce stigma and contribute to broader empowerment of people with disabilities. However, process based inclusion requires a more nuanced approach which is frequently at odds with the demands of output-led poverty reduction strategies. Reporting against more subtle, process-based indicators is more challenging, and few institutional donors have genuinely embraced such an approach, despite an abundance of rhetoric. Clearly new tools are needed to assist mainstream development organizations better identify processes for inclusion which do not end up simply generating beneficiary lists.

Tools for enabling inclusion

One such tool which is being developed is the so-called Umbrella model, which measures household vulnerability to livelihood-related hazards and shocks on a ten-point scale. Whilst
not including disability as a specific measure, the model implicitly identifies household factors which can identify which households are vulnerable, and for what reasons—providing an approach which can differentiate between people with disabilities who would benefit from being a beneficiary, and those who would not—but who would nonetheless have the right to be part of the broader process of the programme. Applying this model to a rural sample of over 1,000 households in rural Myanmar, a consortium of humanitarian agencies was able to identify which households with PwDs were more vulnerable, and for what reasons, and thus engage the community, and people with disabilities, in developing a programme designed to address key issues relating to livelihood vulnerability. This approach was also able to detect vulnerability relating to gender and ageing. This process approach can usefully support double mainstreaming by providing a method which allows greater understanding of underlying causes of poverty, and at the same time facilitating an approach which engages people with disabilities not simply as passive beneficiaries, but as equal right holding participants. Further studies are required to assess the ability of this approach to identify and engage with poverty and vulnerability related to leprosy, but early results are encouraging. For leprosy organizations to successfully enable double mainstreaming, more focus needs to be placed on developing tools and methods to enable identification and understanding of leprosy-related poverty, and to enable inclusion of people affected by leprosy in the broader process of poverty reduction, not simply as beneficiaries. This requires a change in thinking on the part of leprosy-related organizations, away from direct service provision, and towards an advocacy, enabling and facilitative role. We will only reach our goal of elimination of the causes and consequences of leprosy when all stakeholders involved see it as part of their own role in reducing poverty.

References

5. Comparison of gross costs for delivering services to new contacts.