

RECOGNISING DIVERSITY: DISABILITY AND RURAL LIVELIHOODS APPROACHES IN INDIA

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There are approximately 90 million disabled people in India. Concerted action, in both policy and practice, is needed to go beyond welfarism and ensure that these people can participate in and benefit from mainstream rural development programmes. This paper explores how livelihoods-based approaches can improve access by the disabled to resources and entitlements.

Policy conclusions

- For poverty-focused development to follow the core principles of livelihoods approaches, ways must be found of adapting development activity to incorporate the diversity of people
- Livelihood approaches must be sensitive to the existence of persons with disabilities within any target group so that their needs are automatically included in the planning, financing and implementation of mainstream development cooperation activities
- Given funding constraints in most developing countries, together with widespread insensitivity towards disability, support should be given within livelihoods programmes and projects for piloting opportunities for the disabled in a small number of development activities initially
- If inclusion of the disabled is to be sustained within mainstream programmes, policy guidelines will need to establish concrete mechanisms and practices for implementing agencies, including adequate monitoring and follow-up
- Action to allow the rural disabled priority access to employment opportunities and to new business start-up where they can exercise their intellectual skills may be especially appropriate
- However, in rural areas there is limited scope for the physically disabled to exercise their intellectual capabilities. Rural-urban migration is a prominent feature of many developing countries, and there are strong arguments for support to allow the rural disabled to move in order to access opportunities in urban areas
- Self-help groups among the disabled have had some success in influencing policy and practice and merit support

Introduction

Health and fitness, as well as gender and age, affect the likelihood of people benefiting from development programmes in their communities. According to some sources, as many as one person in ten has a disability. Three out of four of those are thought to live in developing countries. 'Disability limits access to education and employment, and leads to economic and social exclusion. Poor people with disabilities are caught in a vicious cycle of poverty and disability, each being a cause and a consequence of the other' (DFID, 2000: 1).

The Indian National Sample Survey conducted two country-wide surveys in 1981 and 1991 to assess the number of people with disabilities. From these it was estimated that the population with a disability in India is approximately 90 million.¹ Within this figure it is estimated that 12 million are blind, 28.5 million have limited vision, 12 million have speech and hearing impairments, 6 million are orthopaedically handicapped, 24 million have a cognitive disability, 7.5 million are mentally ill, and 1.1 million are disabled as a result of leprosy. Estimates vary greatly according to definitions and methods, but negative attitudes towards disability in most communities mean that these are probably underestimates.

India was the first country in South Asia to become a signatory to the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Decade of Disabled Persons 1993–2002. In January 1996, an Act of Parliament enabling implementation of this Proclamation was passed.

The Ministry of Welfare is the nodal Ministry for disability and oversees the provision of welfare benefits to the disabled, including the provision of subsidised food. Unintentionally,

this has 'reinforced a conventional tendency for other Ministries to view disability-related issues as mere welfare matters which have no bearing on their respective mandates and schemes' (CAPART, 1996: 5) (see also Box 2).

The Ninth Plan of the Government of India committed the Government to prepare a National Charter for Social Justice to provide equal opportunities for the disabled. It also proposed the earmarking of a certain percentage of benefits for the disabled under various poverty alleviation schemes, including 3% under a scheme – 'Swamajayanti Gram Swarozgar' (SGSY) – aiming to provide a 'sustainable income' to rural families below the poverty line through self-help groups and micro-enterprise development.

Given the existence of such quotas and welfare benefits for the disabled, some may argue that their needs are already catered for and there is no need to modify other schemes and programmes to include people with disabilities. These arguments are based on rather a limited view of sustainable development, failing to recognise the role played in development by those who are not seen to be working in productive activities.

Despite the efforts of CAPART and others to highlight exclusion, practically none of the rural development projects funded by the Government or donors in India take active steps to include the disabled. Many rural development schemes specifically target poor people who can undertake particular types of wage labour: road building, construction of bunds in the watershed programme or the clearing of irrigation channels. Those unable to undertake such activities often cannot participate in planning or decision-making, nor benefit from the scheme through wages or other means, yet the scheme may actually affect their livelihood, perhaps affecting access to water or some other service.

Box 1 Diversity, disability and society

'We human beings are all different. We have different needs, and different weaknesses. Therefore, the society in which we live should never be formed on the basis of the special demands by the few. The society must be formed in such a way that it will suit all. The needs of disabled persons must influence the planning of our societies as much as the needs of non-disabled persons, not because we must pay special attention to the disabled, but because they are citizens of the society as everyone else. Therefore, their needs must be included in the building of the society as a matter of course.'

Olof Palme, late Prime Minister of Sweden, cited in DFID, 2000: 5

Andhra Pradesh and livelihoods approaches

A Sustainable Livelihoods (SL) approach aims to provide a wider view of poverty than conventional income-based approaches. It recognises the importance of ability to access resources and entitlements, reduce risk and vulnerability, and exercise voice; it therefore emphasises that the poor *do* have assets, options and strategies, and that they are decision-takers; its concern with 'getting below the surface' to informal institutions and processes is particularly important; and it offers the prospect of identifying entry points for pro-poor change, and of sequencing activities in such a way as to minimise the danger of appropriation of benefits by local elites.

The rationale for the promotion of a 'livelihoods approach' in the watershed programme in states such as Andhra Pradesh lies in the desire to take a more inclusive approach to community development and directly address some of the criticism that the watershed programme, which is essentially land-based, does not benefit the poor, many of whom are landless. Such an approach focuses on *people's* livelihood assets and strategies. People's own human capital – comprising the skills, knowledge, ability to labour and good health – is one asset on which they can draw. Hitherto, there has been insufficient differentiation in considering human capital within livelihoods frameworks. In reality, people's human capital exhibits wide diversity – including that attributable to disability – and livelihoods approaches need to reflect this.

The DFID-supported Andhra Pradesh Rural Livelihoods Project (APRLP) covers five districts in Andhra Pradesh, with a total population of over 15 million. The target group for the project are the rural poor in those districts, estimated to be up to 40% of the population. There are likely to be at least 150,000 *profoundly* disabled people in the project's target population, and probably many more affected by some un-enumerated form of disability.

Fluorosis in Andhra Pradesh

Among the disabled in Andhra Pradesh are a group affected by skeletal fluorosis. Whilst the numbers affected by skeletal or dental fluorosis in India are unknown, it is estimated that 70m people in the country are consuming fluoride contaminated water. Andhra Pradesh is one of the seventeen states with known fluoride problems and the ways in which the APRLP might respond to these are discussed below.

In a study of a fluoride-affected area in Andhra Pradesh, van der Sommen et al (1998) concluded that, while the distribution of fluoride seems highly erratic (with some wells in a village having high concentrations of fluoride and others very little), a logical pattern of fluoride distribution could be mapped. They concluded that, from a hydro-geological point of view, it was possible to obtain a safe drinking water supply from the area. However, cultural traditions in many villages relegate 'lower' castes to inferior water supplies.

Also, people who do physical labour in hot climates, such as agricultural labourers (often amongst the poorest groups), consume large volumes of water and, with it, large amounts of fluoride in affected areas. Increased exposure to fluorine contamination is also a supply problem: it is exacerbated when wells dry up, when pumps break down, and when the sinking of additional wells lowers water tables. For these reasons, and because they are unable to avoid the problem by, for instance, buying uncontaminated water, fluorosis is a disease that has largely affected the rural poor in India.

Box 2 The disability-dependency syndrome

The team of representatives arrived at a village in Nalgonda District, Andhra Pradesh, on a typically hot afternoon. Drinking water was foremost in their minds, but not only because of the heat. They had come to hear the villagers tell of their problems with their water supply. As people gathered for a community meeting, Madhavi clutched her sticks and pulled herself towards the visitors, her knees rigid, her hips stiff. 'Do you go to school?' she was asked. 'No' she said, 'I can't sit, I can't run, I can't even walk properly. What are you going to give me?'

Madhavi, just twelve years old, was already severely affected by skeletal fluorosis. She is not alone... later that afternoon, more than 100 pupils mobbed the team as it visited their school. The children were all grinning broadly, not with pleasure, but with the intention of showing yet another group of foreign visitors the staining on their teeth, the telltale brown streaks caused by dental fluorosis.

The people of Madhavi's village, and their local government representatives, wanted a safe water supply. But Madhavi's question was 'what will you give *me*?'. Madhavi expected a personal gift. Her expectation encapsulates the relationship between the disabled and society in India, formed over decades of short-term, welfare-orientated policies and practices.

One of the aims of the APRLP is to improve the quality of and access to natural capital, which includes increasing the overall availability of water through better water management. The programme has the potential to increase the availability of water that is not contaminated with fluoride. However, such development initiatives will not automatically include the most vulnerable groups 'unless more participatory approaches are introduced, the power of elites kept in check, and government funding provided specifically to meet poor people's needs' (Saxena, 2001).

Including the disabled in development

Disability limits access to education and employment, and leads to economic and social exclusion. But perhaps the greatest obstacle to participation and equity is the prevalence of deep-rooted negative attitudes on the part of non-disabled people in the family and community, as well as in Government and in the voluntary sector. The shame some people associate with having disabled kin means that they are often hidden from public view – and as far as 'mainstream' development is concerned, forgotten. This is especially true of females, even those with minor disability being regarded as unmarriageable.

Encouraging a self-help movement of people with disabilities is part of the CAPART strategy to promote the active participation of rural poor people with disabilities in all rural development programmes. Self-help groups of the disabled formed by an NGO – Young India Project – in Andhra Pradesh have been involved in agitations and demands for better conditions (Box 3).

Box 3 Campaigning for the rights of the disabled: the Young India Project

Young India Project is a federation of unions of agricultural and landless labourers who agitate for access to Government employment, income generation, housing, education and health programmes. They also protest against injustice and atrocities committed against the rural poor. In 1998, YIP was working with disabled people in 82 blocks (a cluster of up to 50 villages) in Andhra Pradesh. Their objective there is to facilitate the formation of self-help groups of disabled people who can support each other and campaign for their rights. They not only encourage the disabled to join with farm labourers in agricultural unions (thus providing a route for disabled people to take part in activities in their local community) but also help disabled people to access bank loans, education, housing, transport, land and drinking water.

An NGO called Action on Disability and Development, India (ADD-India), which is based in Bangalore and affiliated to ADD-UK, works in rural South India and supports savings, credit and income generation for people with disabilities. There are many such small initiatives. Another NGO called Amar Seva Sangam works with 4800 disabled people in 330 villages in Tamil Nadu to provide vocational training.

Self-help groups for the disabled which bring people together with the purpose of promoting their development have shown some success, and merit support from donors and governments. They need to be linked to other development initiatives if the disabled are to influence and contribute to the policy and practice of development in their communities.

There are powerful arguments to suggest that the livelihoods of the disabled cannot be seriously addressed if development initiatives embrace only land-based activities, where the main benefit for the landless and marginal farmers is through agricultural labour.

This places limits on the extent to which *rural* development alone can improve the livelihoods of the disabled. Even within this, however, there is scope for creating options for the physically disabled to use their intellectual skills:

- first, affirmative action can be taken to reserve some government positions (e.g. in services such as the post office, banking or line departments) for the disabled;
- second, tax concessions and other incentives can be provided to promote the employment of the disabled or business start-up on their own account in such fields as long-distance telephone booths, internet cafes and other information communication technologies;
- third, there is also an important requirement for providing the disabled with the kinds of technical skill appropriate to such lines of work.

However, it must be recognised that a number of factors combine to make the rural environment a hostile one for the disabled in terms of their access to development opportunities. They tend to be stigmatised within their communities; options for them to use their intellectual capabilities are likely to be few and far between, and mobility to access them restricted. These factors suggest that, where urban options are available and appeal to the disabled, then the most appropriate intervention may be support to allow them to move to urban areas.

The disabled are commonly paraded by fellow villagers to officials and donors in the expectation of attracting benefits to the village. If they are to break out of this 'welfare-beneficiary' role, they must be able to build new social networks. This is where initiatives such as support to self-

help groups for disabled people in rural communities can help to make their voice heard. Within such groups people may also press for access to literacy and numeracy to learn more about their rights. It is important for the disabled to be recognised as full members of the community. At root, disability is a human rights issue.

Sustainable livelihoods approaches need to embrace a 'rights-based approach to development' rather than just a 'needs-based approach' for the disabled (Box 4).

Box 4 Needs-based and rights-based approaches

Needs-based approaches rely on external comparisons between the situation of 'haves' and 'have nots'. Because needs differ between people and contexts, it is difficult to arrive at a universally appropriate definition. Policies and programmes rest on a perception of need as defined by government policy makers. One criticism of the needs-based approach is that it is a welfare approach that subtly reinforces the powerlessness of the poor.

A rights-based approach is based on empowerment, equality of entitlement, dignity, justice and respect for all people. It encourages poor people to demand services actively, according to their own priorities, and thereby raises self-esteem and promotes autonomy. It implies obligations by society to enable people to enjoy their rights, but requires mechanisms for redress if things go wrong.

(see also NRP no. 69)

DFID advocates a twin-track approach to equality for the disabled: combining attempts to account for the needs and rights of the disabled in mainstream development co-operation work as well as supporting specific initiatives aimed at the empowerment of the disabled. Livelihoods approaches can accommodate both strands by including the disabled in participatory development initiatives in the community as a whole and providing particular opportunities, perhaps income earning opportunities, for specific groups of the disabled so that there is a chance for the whole community to benefit from development.

Based on the Strategy outlined in the Government of India's Ninth Plan and adapting policy guidelines published on behalf of the UN by the National Research and Development Centre for Welfare and Health (Wiman, 1996), at the sustainable livelihoods programme and project level there is a need to:

1. identify persons with disabilities within any target group so that provision – and, where necessary, affirmative action – can be built into development plans;
2. develop an appropriate mix of mainstream and specific opportunities for inclusion of the disabled;
3. revise implementing agency procedures, to include:
 - awareness campaigns for all staff;
 - *ad-hoc* advisory groups consisting of persons with disabilities or their representatives, policy makers, technical experts, planners and administrators;
 - employment of disabled people as consultants or advisors in the design and implementation of policy;
 - allocation of an agreed budget for the livelihood development activities of disabled people's own organisations and other organisations working for the benefit of persons with disabilities;
 - development and dissemination of guidelines on the livelihood programme's approach to disability, to all partners, such as consultants, implementing agencies, contractors, and NGOs involved, regardless of funding source.

Conclusion

Much of development has viewed the disabled as an unproductive burden on others, or continues as though they do not exist. Traditional attitudes are deeply entrenched, and to overcome them will take decades. Nevertheless, a livelihoods approach to development focusing on both land and non-land based development, and supporting migration to urban areas where it is a desired option, offers some prospect of including the disabled in development activities. This requires the conscious inclusion of the disabled by others in the community and by government and NGO staff working with communities. This is not a small task, as authors of the CAPART report observe: 'the overall task is to develop replicable approaches and interventions for enabling poor rural people with disabilities to gain greater access to rehabilitation services, opportunities for learning skills and for economic development, infrastructural support for employment and self-employment and opportunities for acquiring their own productive assets'.

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¹Figures from the NSSO surveys cited on www.healthlibrary.com the website of HELP Library on Health Information, Mumbai, India.

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