

Mainstreaming disability
in development:
India country report

EXECUTIVE SUMMARY



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List of abbreviations

ADD	Action on Disability and Development
ADIP	Scheme of assistance to disabled persons for the purchase/fitting of aids and appliances
ALIMCO	Artificial Limbs Manufacturing Corporation of India
APD	Association of People with Disability
CBR	Community-Based Rehabilitation
CCC	Central Coordination Committee
CEC	Central Executive Committee
CSO	Civil Society Organisation
DAD	Delhi Association of the Deaf
DFID	Department for International Development
DPEP	District Primary Education Programme
DPO	Disabled People's Organisation
ERJ	Exclusion, Rights and Justice Team [at DFID]
GoI	Government of India
ICF	International Classification of Functioning, Disability and Health
IED	Inclusive Education of the Disabled
IEDC	Integrated Education for Disabled Children
KaR	Knowledge and Research
MDG	Millennium Development Goal
MHRD	Ministry of Human Resource Development
MSJE	Ministry of Social Justice and Empowerment
NCERT	National Council for Educational Research and Training
NCPEDP	National Centre for the Promotion of Employment of Disabled People
NGO	Non-Governmental Organisation
NFB	National Federation of the Blind
NHFDC	National Handicapped Finance Development Corporation
NHRC	National Human Rights Commission
NPRD	National Programme for Rehabilitation of Persons with Disabilities
NSS	National Sample Survey
OCCPD	Office of the Chief Commissioner for Persons with Disability
PACS	Poorest Areas of Civil Society
PIED	Project Integrated Education for Disabled Children
PRA	Participatory Rural Appraisal
RCI	Rehabilitation Council of India
SCC	State Coordination Committee
SEC	State Executive Committee
SSA	Sarva Shiksha Abhiyan
UGC	University Grants Commission
UN	United Nations
VSO	Voluntary Service Overseas
WHO	World Health Organization

Executive summary

“The situation of disabled people provides a microcosm of the whole development debate and process.”
(Coleridge 1993, p 4)

This report has been produced by the Disability Policy Officer for the Policy Project of the Disability Knowledge and Research (KaR) programme, funded by the UK Department for International Development (DFID). It is last of three studies on disability mainstreaming in countries in which DFID works. The other two studies focus on Cambodia and Rwanda.

These studies have aimed to:

- Explore how disability relates to DFID’s work on reducing poverty and social exclusion and the achievement of the Millennium Development Goals (MDGs)
- Map disability-focused activities in each country
- Identify examples of best practice
- Explore the opportunities and constraints for raising the profile of disability within each DFID programme
- Identify potential partners for DFID to take forward work on disability.

For the India report, the research combined a desk review of documents with the following additional activities, carried out during a 24-day field visit to India:

- Semi-structured key informant interviews
- Focus-group discussions with disabled people
- Home-based interviews with disabled individuals and family members
- Project field visits
- Participation in the second Disability KaR programme roundtable on mainstreaming disability in development, held in Ahmedabad.

Disability in India

India straddles two worlds simultaneously: it is both a developed and developing nation. It is the fourth largest economy in terms of purchasing-power parity, in the top ten most industrialised countries, and a global leader in information technology. It is the world’s largest democracy and a rising power, pressing for a permanent seat on the UN Security Council. However, India is also home to one third of the world’s poorest people, with 350 million people (35 per cent of the population) living on less than US\$1 a day.

Defining disability

There is no universally agreed definition of disability. In this report, disability is understood to be primarily a social phenomenon. It is society that disables people who have impairments, by failing to recognise and accommodate difference, and through the attitudinal, environmental and institutional barriers that it erects against people with impairments. Disability thus arises from a complex interaction between health conditions and the context in which they exist.

In India, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 defines disability as one or more of the following: blindness, low vision, leprosy cured, hearing impairment, locomotor disability, mental retardation and mental illness. It says that to be considered disabled, a person must suffer from not less than 40 per cent of any disability, as certified by a medical authority.

Scale and prevalence of disability

Disability was included in the census for the first time in 2001, following a sustained campaign by the Indian disability movement. The census found that 2.2 per cent of the population were disabled. However, this figure is contested by organisations working in the field, which estimate India's total disabled population at approximately six per cent or 70 million – a figure larger than the entire population of the United Kingdom.

Disability data for India

Total disabled	Male	Female	Urban	Rural
21,906,769	12,605,635	9,301	5,518,387	16,388,382

Source: Government of India (2001)

Disability data for DFID target states

	Andhra Pradesh	Madhya Pradesh	Orissa	West Bengal
Total disabled	1,364,981	1,408,528	1,021,335	1,847,174
In seeing	581,587	636,214	514,104	862,073
In speech	138,974	75,825	68,673	170,022
In hearing	73,373	85,354	84,115	131,579
In movement	415,848	495,878	250,851	412,658
Mental	155,199	115,257	103,592	270,842

Source: Government of India (2001)

Causes of disability

Poverty is the biggest cause of disability in India. The 360 million Indian people who live below the poverty line are the most vulnerable to disability. This is because they are more likely to:

- suffer from malnutrition
- live in crowded and unsanitary conditions, making them more at risk of catching infectious diseases
- have limited access to medical care
- consult traditional healers
- be poorly educated and lack basic knowledge
- not immunise their children
- lack proper care during pregnancy and birth, and have multiple pregnancies.

In addition, poor people are often forced to live and work in unsafe environments. This is due to a range of factors.

In Jammu and Kashmir, more than 17,000 people have been injured in conflict since 1990. Of these, 8,736 were injured by mines. Other factors are related to India's modernisation. Traffic accidents often cause permanent disabling injuries. Disability also arises from poor industrial practices, the use of dangerous pesticides and chemicals, and from fluoride poisoning. Finally, ageing is a major contributing factor to disability, with 36 per cent of the disabled population aged 60 and over.

Disability, poverty and social exclusion

All the informants for this study recognised disabled people as being among the poorest of the poor in India, but none considered disability as predominately a poverty issue. Instead, they saw it as a rights issue. A few linked disability strongly with social exclusion.

Poverty is both a cause and a consequence of disability. Most of the informants in the focus group discussions who had become disabled in later life commented that their disability had made them poorer. The economic costs of disability have three elements:

- direct costs of treatment, including travel and incidental expenses
- foregone income due to disability
- indirect costs to others who provide care and support to the disabled person.

One village-level study in Tamil Nadu found that disability directly and indirectly affects one third of the rural population, and estimated the total costs of disability at approximately 5.5 per cent (Erb and Harriss-White, 2002).

In India, disabled people are seen as passive victims requiring charitable help. All the informants spoke of negative attitudes to disability within Indian society. Disabled informants said they felt they were seen as useless, looked down upon, and treated as objects. "Normally people say you are incapable, you can't do things," one focus group participant explained.

Disabled people in India tend to be:

- over-represented among the poor
- disabled at birth or before school age
- poorly educated
- unemployed
- vulnerable to exploitation and abuse, especially disabled women
- socially marginalised, underestimated and teased.

They tend to lack:

- voice
- access to healthcare, assistive devices and rehabilitation
- vocational training and income generation skills
- access to disability benefits
- confidence and awareness of their rights and entitlements

Disabled people most often live in rural areas, and have difficulty marrying.

The degree of social exclusion that a disabled person will face varies enormously according to his or her status as an individual, as well as the type and severity of the impairment and, in particular, his or her gender. The situation for disabled women is particularly bleak.

The situation for disabled women

Statistics reveal that there are fewer disabled women than men. This reflects the highly gendered nature of Indian society as a whole. Disabled girls tend to receive less care than disabled boys, and are more likely to die or be killed. Where men and women have similar impairments, women are more likely to continue working than their male counterparts and are less likely to seek medical treatment or to see themselves as disabled (Erb and Harris-White 2002, Mohapatra and Mohanty 2004).

Disabled women are less likely to marry than disabled men, and women who become disabled are often divorced or left by their husbands. Disabled women and girls are particularly vulnerable to abuse and exploitation. A study in Orissa found that 100 per cent of the disabled women surveyed were beaten at home, and 25 per cent of mentally challenged women had been raped (Mohapatra and Mohanty 2004). Disabled women are denied their sexuality. They are seen as being incapable of bearing children or of looking after them, so their children are often put into the care of grandparents. The same study found that six per cent of physically disabled women and eight per cent of mentally challenged women had been forcibly sterilised.

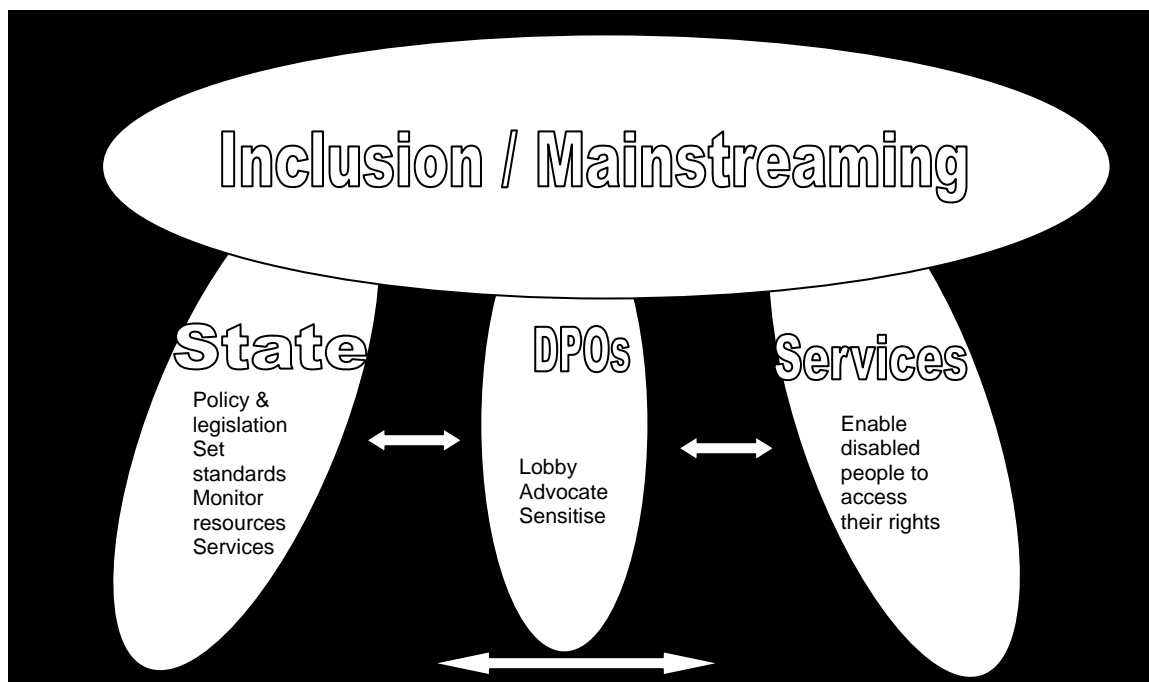
In addition, non-disabled women who give birth to disabled children are often abandoned, and many are physically abused by their husbands.

Disabled people share the profile of the general poor, but they experience poverty more intensely and have fewer opportunities to escape poverty than the non-disabled. Society views them as victims requiring charitable assistance rather than equal citizens with potential. They largely remain trapped in a vicious circle of poverty and social exclusion. Underestimated and undervalued by others, they begin to doubt their own abilities, and the image of the disabled person as a passive victim becomes a self-fulfilling prophecy.

Mainstreaming disability in development in India

There appears to be some confusion in India over the understanding of the terms 'mainstreaming' and 'inclusion'. The confusion is largely semantic, resting on whether mainstreaming is the goal and inclusion the strategy, or vice versa. However, while the terminology may be contested, the meaning of the overall objective is clear: namely, the full realisation of the rights of disabled people to full participation and equality of opportunity.

Three key actors play critical roles in achieving this objective. They are: the state, service providers, and disabled people's organisations (DPOs). The roles and responsibilities of these three, and the dynamics between them, can be visualised as a three-legged stool (see diagram below). Each leg of the stool must be equally strong, otherwise it will be unbalanced. In order to prevent the legs splaying outwards, each of the three actors must work in a coordinated and mutually supportive manner.



The table below summarises the disability sector in India.

Disability sector in India: summary (continued next page)

State	Services	Disabled people's organisations
<ul style="list-style-type: none"> • Comprehensive disability legislation defining rights and entitlement: Mental Health Act 1987, The Rehabilitation Council of India Act 1992, The Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act 1995, The National Trust Act for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act 1999 • Mechanisms for monitoring implementation and redress: Office of the Chief Commissioner in Delhi, state commissioners, and the special rapporteur for disability in the National Human Rights Commission 	<ul style="list-style-type: none"> • National Programme for Rehabilitation of Persons with Disability (six national institutes specialising in different impairments, five composite rehabilitation centres, four regional rehabilitation centres, and an expanding number of district rehabilitation centres) • Production of prosthetics and orthotics, aids and appliances by government company ALIMCO • ADIP – scheme to subsidise access to aids and appliances • Support to civil society providers from the Ministry of Social Justice and Empowerment (MSJE) • Numerous civil society 	<ul style="list-style-type: none"> • No national cross-disability umbrella organisation • Disability rights coalitions consisting of organisations of and for disabled people in Delhi, Kolkata, Chennai and Bangalore • Cohesive disability networks in Gujarat, Maharashtra, Andhra Pradesh, Karnataka, Tamil Nadu, Orissa and Kerala • National Federation of the Blind and All India Confederation of the Blind • Delhi Association of the Deaf, All India Federation of the Deaf and Deaf Way • Growing number of parents' organisations, the largest being Parivaar

<ul style="list-style-type: none"> • Ministry of Social Justice and Empowerment (MSJE) line ministry for disability – provides grants to disability organisations, but budget consistently under-utilised. • Reservations (three per cent) for disabled people in government posts, state educational facilities and poverty alleviation programmes, though reservations not filled • Promotion of inclusive education. 	<p>providers – high quality services but less coverage</p> <ul style="list-style-type: none"> • Some civil-society providers at cutting edge of their fields • State-organised employment exchanges • National Handicapped Finance and Development Corporation (NHFDC) – provides low-interest loans to disabled people 	<ul style="list-style-type: none"> • National Centre for Promotion of Employment of Disabled People (NCPEDP) – provides a focal point for national advocacy, establishing national disability network • Numerous grassroots self-help groups
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Conclusions and recommendations

India has proved an excellent final case study for our research into disability mainstreaming, because it demonstrates that there are no easy answers or quick fixes when it comes to the inclusion of disabled people. In theory, all the key components are in place for success in India, and resources (both human and financial) do not present a significant barrier. However, despite all these positives, in reality, the situation for the average disabled Indian is bleak. The major obstacles appear to be more attitudinal rather than structural.

First, disability is still overwhelmingly viewed as a social welfare issue. As a result, disabled people are seen as passive victims requiring charitable assistance, and disability is considered a ‘special’ issue, isolated from mainstream development. This is a reflection of the broader understanding of rights in the country. In India, rights are claimed less in terms of equality of access than of the notion that certain groups are under-privileged and require ‘special’ assistance.

Second, India’s disability organisations (including organisations both for, and of, disabled people) are underperforming, neither effectively representing the needs of disabled people nor holding the state to account. Broadly, disability organisations are either co-opted or disengaged.

Third, India’s disability rights movement is yet to mature. It is divided along lines of impairment and infused with personal rivalries. These are not unusual problems – they affect the disability movement the world over. However, unfortunately, many of the issues that have been raised by disability activists are largely peripheral to the lives of the average disabled person. Most disabled people in India are unaware of their rights and entitlements. They need empowering, they need information, and they need their concerns to be appropriately represented. Meanwhile, potential opportunities, such as the explosion of the information technology industry in India or planned government legislation on a minimum income for rural workers and the right to information, have so far been given insufficient attention.

The table below presents a detailed situation analysis of disability in India.

SWOC situation analysis of disability in India

Strengths	Opportunities
<ul style="list-style-type: none"> • Comprehensive disability legislation • Mechanisms for monitoring implementation and redress (chief commissioners, National Human Rights Commission) • Adequate financial resources • National rehabilitation plan and national centres of excellence • High quality training for disability professionals accredited by the Rehabilitation Council of India • Strong civil society service providers, some at the cutting edge of their fields • Some well established disabled people's organisations and growing disability rights networks, especially at state level • Growing body of data and research on disability • Donor recognition of disability (World Bank and DFID) 	<ul style="list-style-type: none"> • India's development as a global leader in information technology • Draft government legislation on the right to information and minimum incomes for rural workers • Draft UN Convention on Disability • World Bank interest in disability (Global Partnership for Disability and Development and India Disability Survey) • Use of courts to realise rights and entitlements
Weaknesses	Constraints
<ul style="list-style-type: none"> • Patchy implementation of disability legislation (reservations in employment, education and poverty alleviation programmes not filled, and disability budgets under-utilised) • Difficulties in obtaining disability certificates or accessing government funding • Confused understanding of inclusive education • Disabled people lack information about rights and services • Disability organisations co-opted or disengaged • Dominance of social welfare attitude to disability • Lack of services outside urban areas • High cost and inappropriate nature of government aids and appliances • DPOs unrepresentative, top-down and urban-focused • Lack of a strong, coordinated disability movement 	<ul style="list-style-type: none"> • Corruption • Monolithic Indian bureaucracy • Size and complexity of India

Returning to the concept of disability mainstreaming as a three-legged stool (see p 7), in India the stool is unbalanced. The legs representing the state and services are relatively strong, but the DPO leg is significantly weaker. Indian DPOs need capacity building, but there is an even more urgent need for the three legs of the stool – the state, services and DPOs – to engage with each other, and work in mutually supportive ways.

Currently, disability remains a 'special' issue, divorced from the mainstream. At the state level, disability is somewhat ghettoised within the Ministry of Social Justice and Empowerment, while many civil society players are either government sub-contractors or disengaged, working on their own, or with a few others who share their outlook.

The most interesting and positive examples of practice are those in which disability organisations have moved into the mainstream, or where mainstream organisations have taken disability issues on board. Such cross-overs demonstrate the relevance of disability to poverty reduction and national development. Furthermore, they are essential if disability is break out of its 'special' enclave.

Disability mainstreaming: the role of DFID

Donor aid to India is insignificant, amounting to approximately 0.6 per cent of GDP. This means that donors have very little leverage with the government. Nevertheless, given India's vast population, India's performance on the Millennium Development Goals (MDGs) is critical. In a sense, donor aid may not be very important to India, but India is very important to donors.

Social exclusion is a major barrier to poverty reduction in India, and DFID India has correctly identified this as a critical area in which it can have an impact. Disability is firmly located within this context. DFID India has been exceptionally proactive on disability issues. The key features of its response to disability are:

- **Inclusion of disability indicators in logframe agreements with the government** – Disability-specific indicators are included in Sarva Shiksha Abhiyan programme in education and the Reproductive and Child Health Programme.
- **Partnerships with international NGOs** – DFID India has established its own partnership agreements with selected UK NGOs that have Programme Partnership Agreements with DFID headquarters. Each international NGO partner is to act as a 'nodal point' for a particular excluded group, such as children, or scheduled castes and tribes, to facilitate networking, build capacity and administer grants. Voluntary Service Overseas is the nodal agency for disability.
- **Poorest Areas of Civil Society (PACS) Programme** – The PACS programme is designed to build the capacity of civil society in India's poorest 108 districts. One informant described PACS as "a marvellously thought-out programme". Four disability organisations are currently receiving PACS funding, and proposals are being developed with others, including DPOs.
- **Implementing DFID's corporate diversity agenda** – DFID India has been proactively seeking to implement the corporate diversity strategy, and has seen disability as a priority area. DFID India has been working with the National Centre for the Promotion of Employment of Disabled People (NCPEDP) to ensure that its

recruitment processes are open and inclusive. Efforts have been made to ensure the accessibility of the office.

- **Tsunami response** – A DPO will be taking part in social equity audits in tsunami-affected areas to ensure that recovery programmes proactively address issues of social exclusion.

Recommendations

DFID's programme in India is exceptional in terms of its size and its innovative responses to addressing disability issues as part of wider efforts to tackle social exclusion. The India country office may have more freedom to innovate than offices in countries where the programme is focused on poverty-reduction budgetary support, and Indian disability legislation provides a mandate to act. Nevertheless, its approach to disability issues offers a model that other country offices may find interesting and relevant. The key recommendation is for the India office to continue working as it has.

Below are some suggestions for building on what has already been achieved:

- Support research into the links between disability, poverty and development.
- Include a disability clause in all agreements for funding with civil society (for example DFID's Civil Society Challenge Fund, which requires all applicants to demonstrate how disabled people and children will be included).
- Include disability-specific indicators in agreements with the government.
- Encourage DPOs and disability organisations with a rights-based approach to seek funding from civil society support programmes.
- Include representatives from DPOs and disability organisations in external consultations, and in community monitoring of DFID-supported programmes.
- Ask questions about the implementation of the disability legislation.
- Continue to seek ways to implement DFID's corporate diversity agenda, and to institutionalise disability within this framework.