Disability KaR
Knowledge and Research

Mainstreaming disability in development: India country report

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Contents

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 is 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.

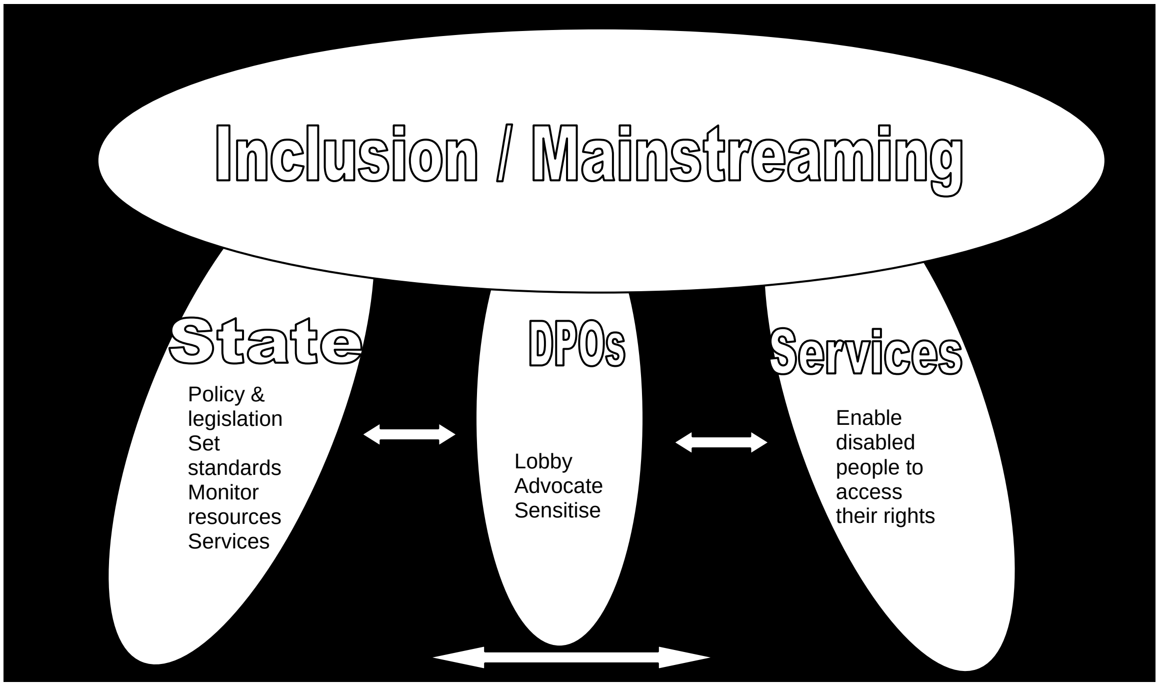
In addition, non-disabled women who give birth to disabled children are often abandoned, and many are physically abused by their husbands.

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
• 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	• 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	• 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, Maharastra, 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

disability in the National Human Rights Commission • 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.	Empowerment (MSJE) • Numerous civil society providers – high quality services but less coverage • 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	• Growing number of parents' organisations, the largest being Parivaar • 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

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 *(cont. next page)*

Strengths	Opportunities
• 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)	• 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**
• 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	• Corruption • Monolithic Indian bureaucracy • Size and complexity of India

Weaknesses *cont.* • 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	

Returning to the concept of disability mainstreaming as a three-legged stool (see p 8), 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 Shiksa Abihyan 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 innovatory 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.

1 Introduction

This report was 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.

The second phase of the DFID Disability Knowledge and Research (KaR) programme began in September 2003 managed by a consortium of the Overseas Development Group at the University of East Anglia and Healthlink Worldwide. The Disability KaR has developed a focus on mainstreaming disability in development.

The programme comprises several components including:

- Carrying out research on disability mainstreaming and the links between disability and poverty
- Developing training courses on disability and development
- Holding regional roundtables on disability and development themes
- Disability policy project, which has placed a technical adviser (the Disability Policy Officer) on disability issues within the policy division of DFID.

One of the first activities of the Disability Policy Officer was to complete a report mapping DFID's current activities to support disability worldwide. The main findings of the report were as follows:

- DFID has not mainstreamed disability, but there is a solid bedrock of disability-specific activities being carried out, largely via NGOs and civil society organisations (CSOs).
- DFID's work on disability is largely hidden, and often DFID staff and country offices are unaware of disability-focused activities being carried out by NGOs and CSOs.
- While broadly recognising the links between poverty and disability, DFID staff do not necessarily see disability as an essential part of their work on poverty reduction and towards achieving the Millennium Development Goals (MDGs).
- DFID staff need more information on disability – in particular, practical tools and examples of best practice – to enable them to implement the twin-track approach outlined in DFID's issues paper *Disability, Poverty and Development* (DFID 2000).

It was decided to follow up this mapping by conducting three studies on disability mainstreaming in three countries in which DFID works. These studies aimed to:

- Explore how disability relates to DFID's work on reducing poverty and social exclusion and the achievement of the 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.

Specific terms of reference are agreed for each country. This India report is the last of the three studies, with research in Rwanda and Cambodia already completed. A final report synthesising the findings from the country research will be produced.

The Disability Policy Officer works closely with the Exclusion, Rights and Justice (ERJ) team within DFID Policy Division. DFID is due to publish a position paper on social exclusion. It is hoped that this study will contribute to this new strategy.

Methodology

The research for this study was conducted by the Disability Policy Officer. The research comprised a desk review of literature and a 24-day field visit to India during February and March 2005.

The primary research method was key informant interviews. (For a full list of interviewees, see Annex 1, p 56). Field visits were conducted to:
- Amar Jyoti, New Delhi
- Samadhan, Dwarka, New Delhi
- Basic Needs Urban Mental Health Programme, Bangalore
- Richmond Fellowship Half-Way House, Bangalore
- Action on Disability and Development programme, Jangamote, Kolor district, Karnataka
- Mithra Jyoti, Bangalore
- Association of People with Disability (APD) Centre and Horticultural Centre, Bangalore.

Focus-group discussions were held with 26 disabled people in Jangamote, Kolor district, Karnataka, and with 12 disabled trainees at the APD's Horticultural Centre. A small number of individual interviews with disabled people and/or their parents and carers were conducted in Dwarka, New Delhi, Bangalore, and in Kolor district.

The research was also informed by the discussions at the second Disability KaR Roundtable, 'Mainstreaming Disability in Development', held in Ahmedabad on 24-26 February 2005.

Constraints

Due to the sheer size and complexity of India, and the short research period, this report is by no means comprehensive – it merely offers a snapshot. Efforts were made to contact a range of organisations, including international and local NGOs and disabled people's organisations (DPOs) spanning a variety of different disabilities, but these represented only a tiny fraction of the number of organisations in the sector. Examples of best practice identified in this report are highly selective – many other examples undoubtedly exist of which the author is not aware.

The disabled people who were interviewed, took part in the focus group discussions, or contributed during field visits cannot be said to be representative of the majority of disabled people in India. This is because all the individuals concerned were receiving some support from a disability organisation, or were involved in a self-help group, while the majority of disabled people in India receive no such support. However, where possible – such as in the focus group discussions – efforts were made to ensure that the participants were of different ages and gender, and had a range of impairments.

Outline of this paper

Section 2 following provides a summary of disability in India, examining the existing data on disability rates, prevalence and causes. Section 3 looks at disability in relation to poverty and social exclusion. It seeks to provide insight into the lives of disabled people, based largely on the interviews and focus group discussions with disabled people and small-scale research. Section 4 provides an examination of mainstreaming, highlighting some examples of best practice. Conclusions and recommendations are presented in the final section.

Acknowledgements

The author would like to thank all those who provided information for this study and participated in interviews. In particular, thanks are due to all the disabled people who I met and interviewed, and who generously shared details of their lives and often very painful memories. In particular, the author greatly appreciated the time and effort spent by staff of Voluntary Services Overseas (VSO) India and Action on Disability and Development (ADD) India in arranging the schedule and facilitating meetings.

2 Disability in India

> "Indian society invisibilises disabled people."
> Harsh Mander, Centre for Equity Studies, interview 2005

Defining disability

There is no universally agreed definition of disability. Historically, disability has been seen primarily as a medical condition – a problem located within the individual. Since then, this medical or individual model has been challenged by disability activists who reconceptualised disability as primarily a social phenomenon. This social model of disability draws a clear distinction between 'impairments' and 'disability'. It argues that it is society that disables people with impairments, through its failure 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.

This social understanding of disability has gained widespread acceptance, and is reflected in the UN World Programme of Action for Disabled Persons, the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, the World Health Organization's International Classification of Functioning Disability and Health (ICF), and by the World Bank, DFID and others.

Understanding of disability 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. The medical understanding of disability clearly informs the act, but its tight and selective definitions of disability, and its 40 per cent threshold, means that some key disabilities, such as autism and other spectrum disorders, haemophilia, thalassaemia, severe facial disfigurement, and individuals with more mild disabilities, are excluded.

What disability means to disabled people and their families *(cont. next page)*

"I've got this disability. My son asked me to read to him. He is in grade 1. I couldn't do it – it was the most embarrassing thing in my life."
41-year-old blind man, Kolor district, Karnataka

"I want my son to be a useful and productive man – this is my dream."
Mother of son diagnosed with schizophrenia, Bangalore

"Normally people say you are incapable – you can't do things."
Physically disabled man, Kolor district, Karnataka

"Before disability, I was living a peaceful life. Now I am not."
Physically disabled man, Kolor district, Karnataka

"As an individual, I don't have any regret. But others underestimate me. They keep reminding me of what I cannot do."
Young man, disabled at an early age from polio, training to be a horticulturalist in Bangalore

"'Because I cannot see well, it is easy for me to ignore things I don't like. I cannot spend every day comparing myself with others."
Man with low vision, working for a disability organisation, Karnataka

Interviews, Bangalore, and Kolor district, Karnataka

Scale and prevalence of disability

In 1991, the National Sample Survey (NSS) estimated India's disabled population to be 1.9 per cent, or 1.62 *crores*[1]. India has carried out national censuses every 10 years since independence, but data about disability had not been collected. This changed for the 2001 census, following a sustained campaign by the disability movement.

Disability data for India

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

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In movement	415,848	495,878	250,851	412,658
Mental	155,199	115,257	103,592	270,842

Source: Government of India (2001)

For budgeting purposes, the Planning Commission uses a figure of four per cent of the population as being disabled. However, the real figure could be substantially higher. Organisations working in disability do not consider the census data to be accurate. They estimate India's total disabled population at approximately six per cent of the total population, or 70 million – more than the entire population of the United Kingdom. The World Health Organization (WHO) estimates that 10 per cent of any given population are disabled. It is likely that India's disability rate is within a range of 4–9 per cent, which would be comparable with other countries.[2]

The reasons for the low figures in the census include:

- Failure of families to disclose disabled household members

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[1] One crore = 10 million.

[2] The proportion of people who are disabled in China is five per cent, Sri Lanka 5–8 per cent, and Cambodia 10–15 per cent according to the Asian Development Bank (ADB).

- Inability of families to identify mild disabilities
- Poorly trained, low-paid enumerators who, according to anecdotal evidence, may often neglect to ask the questions about disability
- Women being less likely to see themselves as disabled than men.

(Erb and Harriss-White 2002, Mohapatra and Mohanty 2004)

Despite its shortcomings, the census clearly reveals that the majority of India's disabled people live in rural areas, have movement difficulties, and are men.

The gender disparity reflects the highly gendered nature of Indian society as a whole. Nationally, the numbers of women to men are 933 per 1000 (VSO 2005). There is a general preference for male children in India, which promotes female foeticide and infanticide. Girls are often neglected and receive less food than boys. They are also less likely to be educated. If girls and women in general are not valued, then disabled girls and women are likely to be even less so. In addition, studies reveal that where men and women have similar impairments, women are more likely to continue working and carrying out household tasks, less likely to seek medical treatment and see themselves as disabled (Erb and Harriss-White 2002, Mohapatra and Mohanty 2004).

Causes of disability

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

- suffer 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.

In addition, poor people are often forced to live and work in unsafe environments.

Disability and conflict: Jammu and Kashmir *(cont. next page)*
Since independence, war between India and Pakistan has broken out twice over the territory of Jammu and Kashmir. Conflict generates disability – both directly, through mines, bullets and bombs, and indirectly, through the breakdown of health and immunisation services.

Since 1990, more than 14,454 civilians have been killed and a further 17,181 injured (Indian Army 2005). The risk of mine injury dramatically increased when 2,897km of the Pakistan-India border was mined between December 2001 and July 2002. Mines were laid as far as 6–8km from the border. According to the Indian Army, 1,041 civilians were killed and 8,736 injured between 1990 and 2001 due to mines and improvised explosive devices. People living in areas of conflict, especially along the line of control, suffer from physical and psychological trauma and deteriorating health conditions.

Disability and conflict *cont.*

The Sarva Shiksha Abhiyan (SSA) programme reports high incidences of disabilities in children (post-polio paralysis, cerebral palsy) attributed to reduced coverage of immunisation programmes and poor access to medical services (Sarva Shiksha Abhiyan 2005).

Specialist services (prosthetics and orthotics, physical rehabilitation) are insufficient and generally urban based. There are no follow up or repair and modification services available.

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, with 36 per cent of the disabled population aged 60 years and over.

3 Disability, poverty and social exclusion in India

India straddles two worlds simultaneously. 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. India is home to the world's largest middle class and the largest democracy. It is a global power, and is 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 (35 per cent) of the population living on less than US$1 a day. It has one of the highest infant mortality rates (67 per 1000 live births) and maternal mortality rates (540 per 100,000 live births). Over half (53 per cent) of children under five are malnourished, 33 million children have never been to school, and nearly 36 per cent drop out before completing primary education. India also has the world's largest population of illiterate people. The performance of India is critical to the global achievement of the Millennium Development Goals (MDGs).

Conceptual understandings

A holistic conceptualisation of poverty, encompassing concepts such as vulnerability, voicelessness and access to services, as well as income deprivation, is widely understood in India. The concept of social exclusion is well understood, and used widely to explain India's poverty dynamics. It is particularly pertinent in India, which some have labelled the most discriminatory society on earth.

DFID's working definition of social exclusion is:

> "…the experience of certain groups who suffer discrimination on the basis of their social identity and are excluded from economic, social or political opportunities as a result. This discrimination may operate at the level of state policy, institutional bias, social practices, or historic neglect."
>
> Chambers 2005

Social exclusion complements holistic understandings of poverty by adding a dimension of causality – namely, that someone, or something, is 'doing' the excluding. It is a particularly useful concept for understanding the dynamics of disability and poverty because it chimes with the social model of disability, which emphasises the institutional, attitudinal and environmental barriers in society that disable people with impairments.

All the informants for this study recognised disabled people as being among the poorest of the poor in India, but none saw disability as predominately a poverty issue. Instead, they saw it as a rights issue. A few also linked disability strongly with social exclusion. This was in marked contrast to the informants for the Cambodia and Rwanda reports, who saw disability clearly as a poverty issue, and none of whom saw disability as a rights issue. This may be because notions of rights are well understood in India, which has a history of unbroken democracy since independence, and a strong and independent judiciary and mature legal system. Furthermore, poverty is not the dominant issue in India, and most of the informants for this study were middle class and urban based. Few were directly involved in working with poor communities.

There is no national data on the nature and depth of poverty experienced by disabled people compared to non-disabled people. As a result, evidence for this section is largely qualitative, drawn from interviews for this study, from two focus group discussions: one with disabled people in Kolor district in Karnataka, and one with students at a vocational training course in Bangalore and home interviews with individual disabled people in Delhi and Kolor district.

This section also draws heavily on two documents. The first is a small-scale study into domestic violence and disabled women in Orissa (Mohapatra and Mohanty 2004). The second is a larger participatory rural appraisal study covering seven *talukas*[3], 55 villages and eight urban slums in four districts of Gujarat (UNNATI 2004). These documents were used in conjunction with the wider literature on disability in India. The sheer size and complexity of India, with its huge variations in poverty, mean that it is not possible to give a comprehensive picture of the situation of disabled people. Nevertheless, this section aims to provide a glimpse into the lives of some disabled people, and to capture some of their voices and stories.

The situation of disabled people in India

Disability and poverty

Poverty is recognised to be a major cause of disability in the developing world. Most disability is preventable or treatable (DFID 2000, Elwan 1999). Poor people lack access to basic health care, so simple infections, illnesses and injuries often result in permanent disability because they go untreated or are mistreated.

In the Gujarat study (UNNATI 2004) mentioned above, 70 per cent of the disabled people identified were disabled before school age. This is a surprisingly high figure, and points to the impact of India's high rates of malnutrition among the under-fives, maternal mortality, and poor early childhood care. Malnourishment is a major cause of developmental delay and long-term intellectual disability.

Historically, India has a poor record of immunisations. Until very recently, polio has been a major cause of disability. In an interview for this study, a paediatrician working for a NGO helping intellectually challenged children in a slum area in Delhi said: "Most of the disability is preventable – multiple pregnancies, poor nutrition, poor ante-natal care." Grinding poverty often brings psychosocial mental health problems such as depression and anxiety, which can be very disabling and to which women are particularly vulnerable.

Poverty is not only a cause of disability: it is also a major consequence of disability. Most of the informants in the focus group discussions who became disabled in later life commented that disability had made them poorer.

> "My earning has really come down."
>
> "If people become disabled, they get trapped financially. They have to pay a lot for healthcare and rehabilitation."
>
> Focus group participants

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[3] An administrative division in India below a district

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.

A village-level study in Tamil Nadu attempted to quantify these costs. It found that the average cost of disability, affecting approximately nine per cent of the rural population, was more than eight per cent of total income in the areas studied. Based on this finding, it suggests that losses due to incapacity amount to two or three times the estimated productivity losses resulting from poor nutrition (Erb and Harriss-White 2002).

Attitudes towards disability

All the informants spoke of negative attitudes towards disability within Indian society.

> "Disabled people in Indian mythology as well as history have been depicted as cruel and spiteful."
>
> Bhambani in Hans and Patri 2003, p 73

Some see disability as a punishment for sins – particularly in the case of those who become disabled later in life, rather than at birth or in early childhood. Disabled informants spoke of feeling seen as useless, looked down upon and treated as objects. One focus group participant explained, "Normally people say you are incapable – you can't do things."

Many disabled children are hidden away, neglected or receive less food and care within the family than non-disabled children. However, some children are given special care and attention because of their disability. A minority of the focus group participants spoke of having been given more attention, and of being seen as more important than their non-disabled siblings. For example, Shruti, disabled in one leg from polio at the age of four, was the only one of the family's four children to be given a private education. Informants often spoke of disabled children being over-protected. This was particularly the case for blind people – especially for blind girls and women, who were seen as no longer being capable of doing the most basic household tasks, or of going out on their own.

Attitudes towards disabled people are complex, and vary according to type of impairment and different social, community and family dynamics. People with mental health problems tend to suffer the most discrimination, and individuals with learning and intellectual difficulties are often seen as being mentally ill. Nevertheless, the dominant attitude towards disability is one of social welfare. Disabled people are seen as passive victims requiring charitable help.

One point of interest during the visit was that the author encountered three beggars who were pretending to have a disability. One had smeared something on her face and claimed that she had been burned. Another had fabricated a false stump to wear on her arm, and one had acquired a pair of crutches and held his leg as if it had been affected by polio. Clearly, disability is seen as an asset in terms of begging.

Case study: Rajesh

Rajesh is 32. He lives with his mother, sister and nieces in his brother-in-law's tiny two-room house in a slum in Bangalore. Five years ago, he was the family breadwinner, earning 350 rupees a week. Then one day he suffered a head injury at work. As a result, his personality changed dramatically. He became very violent and he started to attack his mother, sister and the children.

His family did not know what to do. They took Rajesh to the hospital, and he was diagnosed with schizophrenia and given medicine. However, the family could not afford further treatment, and Rajesh quickly relapsed. They tried faith healers but to no avail. Sometimes they just used to chain Rajesh up. Rajesh was unable to work, and for five years the family has survived on the small income that Rajesh's sister made as a maid, and from his nephew's work as a bar tender.

Rajesh was also abusive and sometimes violent towards the neighbours and people passing in the street. Friends stopped visiting, and the community started to isolate the family. On one occasion, neighbours severely beat Rajesh.

A disability organisation working in mental health issues identified Rajesh, and helped him to return to the hospital. He has now been taking medication for two months. It is early days, but Rajesh's family have seen remarkable changes. His mother said, "I am relieved – I feel I am peaceful now. He is silent. If this kind of improvement continues, I will be the happiest person."

Rajesh is now thinking about returning to work. He will need to take medication for the rest of his life, but thanks to the work of the disability organisation, the local hospital has agreed to provide free drugs for mental health patients below the poverty line.

Interview, Bangalore

Social exclusion

The degree of social exclusion faced by disabled people varies enormously according to an individual's status, as well as the type and severity of the impairment and, in particular, his or her gender.

Disabled people lack voice. During the participatory rural appraisal (PRA) work in Gujarat, it was noted that disabled people sat at the back and participated only when specifically asked to do so. They felt embarrassed to express their opinions in front of others since they had never done this before, and when they did attempt to talk, in 44 per cent of cases they were interrupted by family members, *sarpanch* [4] or others in the group. This discouraged them, and some left early – especially the women (UNNATI 2004).

Disabled people find it difficult to marry. In the Gujarat study (UNNATI 2004), 54 per cent of the disabled adults were not married. Of those who were, 59 per cent were disabled men and only 41 per cent disabled women. One per cent of the respondents were divorced. In many cases, the reason for the divorce was the spouse having become

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[4] Sarpanch is the local headman or village leader

disabled. There were many more cases in which couples were not divorced but lived separately.

> "Many men also force their disabled wives to leave home so that they can live with other women. Women on the other hand continue looking after the needs of the husbands and families even when their husbands are disabled and unable to earn a living."
>
> UNNATI 2004, p 22

Discussions revealed that disabled men look for non-disabled partners whereas disabled women are either married to disabled men or men who belong to socially or economically weaker groups. The Orissa study (Mohapatra and Mohanty 2004) found that only 30.5 per cent of the disabled women were married. Disability in the family also negatively impacts on the marrying potential of non-disabled girls (Coleridge 1993).

Disabled women are denied their sexuality. They are seen as being incapable of bearing children, and are often judged incapable of looking after their children, so their children are often put into the care of grandparents. In general, Indian society pressurises women into motherhood, but disabled women are prevented from having children. The Orissa study found that six per cent of physically disabled women and eight per cent of mentally challenged women had been forcibly sterilised (Mohapatra and Mohanty 2004).

Non-disabled women who give birth to disabled children are often abandoned by their husbands, and many are physically abused by their husbands. They blame themselves for their child's disability, and some believe that they are cursed because of their misdeeds. They are ashamed and often want to hide the child. A community worker who had been helping intellectually challenged children and their mothers in a slum area of Delhi for 18 years commented that most of the mothers of such children end up having to survive on their own.

Disabled people are often excluded from social and religious activities in their communities. This is particularly the case for disabled women. In the Orissa study, only 42.4 per cent of women with physical, hearing or visual impairments went out of the house regularly. For mentally challenged women, this figure fell to 27.6 per cent (ibid).

Disabled women, particularly those with intellectual and hearing disabilities, are very vulnerable to abuse. The Orissa study found that 100 per cent of the disabled women were beaten at home, and 12.6 per cent of women with physical, visual and hearing impairments had been raped, with the figure rising to 24.6 per cent of women who were mentally challenged. Most women did not report the abuse to others – even family members – and when they did report, the overwhelming reaction was to pretend that it had never happened. The report notes that "abuse of women with disabilities is a problem of epidemic proportions" (ibid, p 21).

In addition to society's negative attitudes towards them, disabled people face numerous environmental and physical barriers. They are often left out of mainstream society because most public places are inaccessible, and roads, transport and public buildings are designed for the non-disabled. Disabled people also lack access to information. In particular, informants said that very few disabled people are aware of their rights and the benefits to which they are entitled. Very little information is available in formats that are accessible for visually- and hearing-impaired people. One focus group participant commented, “Non-disabled people have more information.” The cumulative effect of these barriers is exclusion from educational, economic, social and cultural spheres, as well as development.

Access to services

Time-consuming and cumbersome government procedures and corruption both act as additional barriers that prevent disabled people from accessing services. Most informants noted the difficulty in obtaining disability certificates, required in order to access state subsidised disability services and entitlements. In the Gujarat study (UNNATI 2004), 71 per cent of the disabled people had certificates, but 19 per cent did not know about the certificate at all.

The situation varies enormously across the country, but in general, the main problems in accessing disability certificates were:

- Lack of medical boards to issue certificates in districts
- Lack of information about documents needed to obtain disability certificates
- Physical and cost barriers in obtaining certificates
- Lack of qualified doctors certified to issue certificates for intellectually disabled and mentally ill people
- Corruption.

Even with a disability certificate, benefit entitlements vary enormously across the country. Only 40 per cent of the participants in the focus group held in Kolor district, Karnataka, were receiving the state disability allowance, despite being active members of disability self-help groups and Karnataka being one of the most proactive states on disability issues. In Gujarat, most disabled people who had a certificate had used it only to access certain benefits, such as a bus pass and educational scholarships. Only three per cent had received monetary support from the government on a regular basis (UNNATI 2004).

Health

Cost and distance remain significant barriers for poor people in India, especially the rural poor, in accessing health care. For disabled people, these barriers are intensified, as they generally require more health care and their impairments often make travelling more difficult. Specialised rehabilitation services are generally inadequate and particularly lacking outside urban areas.

The Gujarat study (UNNATI 2004) found that only 25 per cent of the disabled people were using aids and appliances. Even if disabled people can access assistive devices, these are often inappropriate, and repair and maintenance are very difficult in rural areas. Appliances from ALIMCO, the government provider, are generally recognised to be of poor quality, and accessing them can be very time-consuming and bureaucratic.

Mobility India, an NGO that has been pioneering low-cost aids, is also critical of the government’s assessment procedures. The organisation has been working with the government in one district in Tamil Nadu. The government assessed approximately 400 disabled people and found that 57 of them needed devices and requested Mobility India to provide them. When Mobility India reassessed the disabled people, it found that in fact, nearly 300 of the 400 disabled people needed aids. In addition, village health workers lack knowledge about disability particularly mental health and intellectual disabilities.

Numerous NGOs provide specialist rehabilitation services. The quality of these services is usually higher than those provided by the government, but coverage is limited, and few disabled people have access to information about these services. In the course of this research, the author was struck by the number of disabled people encountered who have travelled very large distances, often from different states, to access NGO rehabilitation services. In most cases, the individuals had heard about the services from family members, or people in their communities. This highlights the paucity of quality services available to disabled people, and the very considerable lengths to which some individuals, with even fairly modest means, will go to access assistance.

Education

Disabled people experience unequal access to education. It is thought that only four per cent of disabled children have access to education (Office of the Chief Commissioner of Persons with Disabilities 2003), while surveys carried out by the Ministry of Human Resource Development (MHRD) and the National Council of Educational Research and Training (NCERT) suggest figures of less than one per cent (Singhal 2004). The 58th round of the National Sample Survey found that only 45 per cent of disabled people were literate and just nine per cent had completed secondary education or above (NSS 2002, cited in World Bank 2004).

The Gujarat study (UNNATI 2004) found 43 per cent of the disabled people it surveyed to be literate, but only 35 per cent of these were women. As in Indian society in general, there are strong gender disparities in education. Disabled girls are less likely to attend school than other children, and are more likely to drop out. Also, parents of disabled girls are worried about the vulnerability of their girls to exploitation and abuse and thus nervous about letting them travel to school.

There are significant physical barriers preventing disabled children from accessing schools. While primary schools exist in most villages, there are significantly fewer high schools, and despite efforts to incorporate ramps and rails, most school buildings remain unmodified.

According to the Rehabilitation Council of India (RCI) there are approximately 2,500 special schools, which are located mainly in urban areas and run by NGOs and voluntary organisations (Singhal 2005).

Government policy on education broadly advocates a twin-track approach promoting inclusive education for most disabled children, alongside special schooling for those for whom mainstream schooling is inappropriate. However, understandings of inclusive education are somewhat confused, and the approaches of the Ministry of Human Resources Development and the Ministry of Social Justice and Empowerment are uncoordinated.

Education is discussed in greater detail on p 44.

Disability and livelihoods

Disability significantly impacts on a person’s potential to earn a living. An estimated 75 per cent of disabled people are unemployed (VSO 2004). In the Gujarat study, 53 per cent of the disabled people surveyed were not earning (UNNATI 2004). The 1995 Persons with Disabilities Act mandated a three per cent reservation for disabled people in government jobs, but these still tend to be confined to lower-grade posts, and in reality, many disabled people find it extremely difficult to access them. The government has also established employment exchanges for disabled people, but on the whole these have failed, and have become “more or less debunked” (Planning Commission, cited in NCPEDP 2004, p 24).

The Persons with Disabilities Act requires the government to provide incentives for public and private sector employers to make sure at least five per cent of their workforce is made up of disabled people, but no such incentives appear to have been developed. Less than one per cent of jobs in the private sector are held by disabled people (NCPEDP 2004).

Approximately 80 per cent of employment in India – especially in rural areas – is in the informal sector. Income-generation skill training for disabled people is still very limited. In the Gujarat study, only seven per cent of disabled people aged 18 to 45 had received any formal vocational training. Most had been trained by family or community members in limited skills such as basket making, weaving, embroidery or typing. However, these skills did not really help them to earn a living, and many ended up doing manual work for a pittance (UNNATI 2004).

In the 1990s, thousands of jobs were created in India, especially in the information technology industry, but disabled people are excluded from these opportunities. A survey of blind hawkers in Greater Mumbai found that 40 per cent were educated to secondary level and three per cent had graduate and postgraduate degrees. About one third had received some vocational training from NGOs, but they said this was not helpful in getting them work (India Centre for Human Rights and Law, cited in NCPEDP 2004a).

Case study: Kumar

Kumar, aged 34, is married with one child. He lives in a village in Kolor district, Karnataka. In 1998, he fell from a tree and broke his spine. Luckily, his family was relatively well off so they paid for him to attend a private hospital in Bangalore, recommended by the local doctor. At the hospital, he learned skills so that he could adjust to his new life as a paraplegic. The local church gave him a wheelchair and he returned to his village.

His disability has had a huge impact on his life. At first he found it very difficult to cope. He could no longer work in the fields, and he felt as if he were dependent on his brother and could not support his family. Then he started managing the small flour mill that his family owns. The family built a ramp so that Kumar could get inside the mill and he is now becoming a successful small businessman. Kumar has surmounted many challenges but he realises he is also lucky because his family had means: “If this happens to a poor man, then he has to just sit in the corner and then you get mental depression.”

Interview, Kolor district, Karnataka

There is a serious lack of quality vocational training for disabled people. This is compounded by the lack of access to education, and society’s negative attitudes. The result is that the vast majority of India’s disabled population are unable to reach their potential, remain dependant on families for support, and are denied the opportunity to contribute to the country’s development.

Disabled people are over-represented among the poor in India, and many are the poorest of the poor. Disabled people share the profile of the general poor, but they also experience poverty more intensely, and have fewer opportunities to escape poverty than the non-disabled. Society views disabled people as victims requiring charitable assistance rather than equal citizens with potential. They are socially excluded, undervalued, and lack access to education and employment.

There is little appreciation in society of the abilities of disabled people. In the Gujarat study, 75 per cent of the non-disabled respondents were unsure of the abilities of disabled people. This impacts negatively on disabled people’s own estimation of their value: 53 per cent of the disabled people in Gujarat were unsure of their abilities (UNNATI 2004). Disabled people in India 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.

4. Mainstreaming disability in development in India

> "Disability should not be looked at as an exclusive issue."
> Dr Ali Baquer, Concerned Action Now, interview 2005

> "The only real enduring thing is empowerment in terms of rights."
> Colin Gonsalves, Human Rights Law Network, interview 2005

In order to mainstream disability in developement, three key actors – the state, service providers and disabled people's organisations (DPOs) – are critical. The roles and responsibilities of these actors and the dynamics between them can be visualised as a three-legged stool, which supports and upholds the goal of 'inclusion' or 'mainstreaming'.

The first leg of the stool is the state, whose role is to recognise and enshrine the rights of disabled people, and define responsibilities in legislation and policy. This can take the form of specific legislation and policy, or a comprehensive review of existing legislative and policy commitments, to ensure that the rights of disabled people are adequately protected and discrimination removed.

The state is also responsible for:
- Setting and monitoring standards
- Providing resources dependent on the development of the nation
- Providing services – in particular, making sure that mainstream services, such as health and education, are fully accessible to disabled people.

The second leg of the stool comprises specialist services for disabled people, such as physical and socio-economic rehabilitation. These are essential to minimise the impact of individual's impairments and to enable disabled people to access their rights.

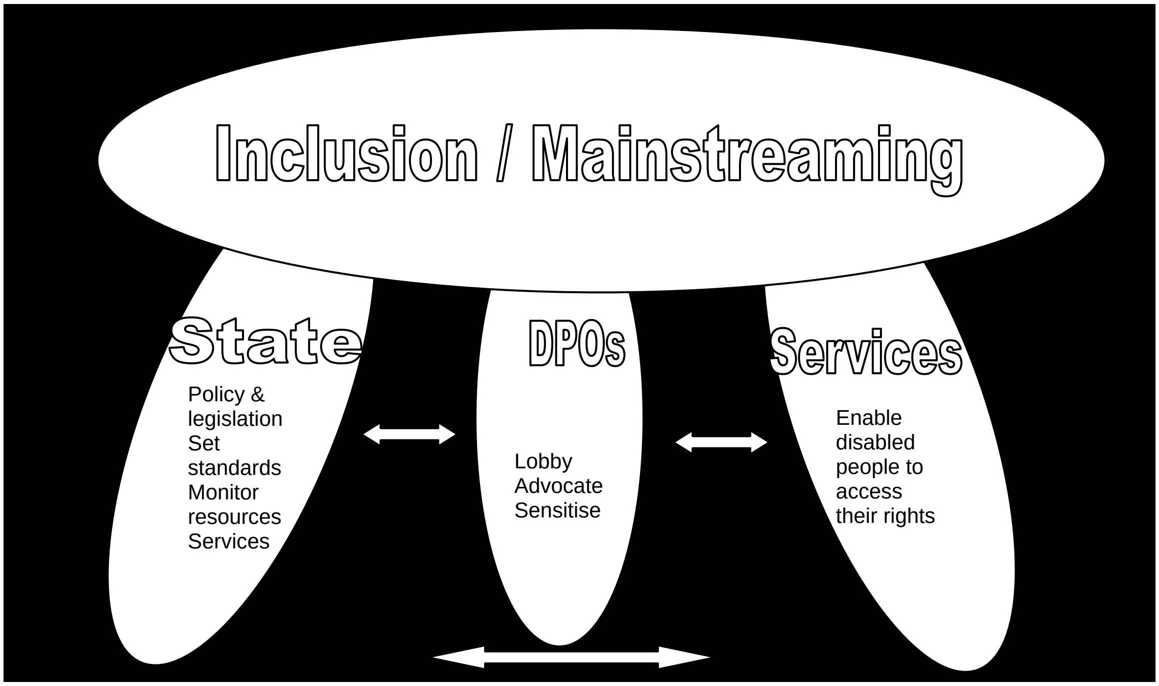
The final leg of the stool is made up of disabled people's organisations (DPOs). These are organisations led and managed by disabled people themselves. Their role is to represent disabled people, to advocate and lobby for their rights, and to ensure that the state and service providers are responsive to their needs.

Each leg of the stool must be equally strong, otherwise it will be unbalanced. In order to prevent the legs from splaying outwards, all three groups of actors – the state, DPOs, and service providers – need to work in a coordinated and mutually supportive manner. (See diagram, next page.)

The state

The legislative framework for the protection of the rights of disabled people are covered by four acts:
- Mental Health Act 1987
- Rehabilitation Council of India Act 1992
- 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

Three-legged stool



Mental Health Act 1987

This Act replaced the Indian Lunacy Act of 1912 and aims to introduce changes based on modern understandings of mental health and to consolidate treatment and care practices in line with modern practices and values. Outmoded language was replaced, admission and discharge procedures simplified and psychiatric hospitals have to be licensed. The Act removed mental retardation from under the definition of mental illness.

The Rehabilitation Council of India Act 1992

This Act relates to the training of professionals in 16 disciplines within the rehabilitation sector. It seeks to ensure that disabled people are treated by qualified personnel, and acts as an accreditation and quality control facility. The Act requires everyone practising rehabilitation to register with the RCI's central rehabilitation register, but this is only possible with a government-recognised diploma. Following NGO lobbying, the Act has been diluted so that locally trained NGO personnel can be accredited after attending short bridging courses at a range of government-approved training centres.

The Persons with Disabilities Act 1995

This is the central government piece of legislation. The main provisions include:

- Prevention and early detection (section 25)
- Free education for every child with a disability in an appropriate environment until the age of 18 (section 26a)
- Schemes and programmes for non-formal education (section 27)
- A three per cent reservation admission to all government education institutions (section 39)

- A three per cent reservation in all government poverty alleviation schemes (section 40)
- Barrier-free environments in transport and government buildings (sections 44–46)
- A three per cent reservation in government posts and identification of posts for disabled people (sections 32a and 33)
- Special measures to overcome discrimination, such as preference in allotment of land for housing, business, special schools, research and recreation centres, and factories (section 43)
- Generic and specialised rehabilitation services (section 66)
- Insurance scheme for disabled employees (section 67)
- Unemployment allowance for out-of-work disabled people (section 68)
- Coordination and monitoring (chapters 2 and 3, sections 3–24)
- Appointment of a commissioner in every state to follow up complaints (section 62).

To access the benefits of the Act, a disabled person must have a ‘disability certificate’, which is obtained after an assessment by certified government medical personnel. The assessment must find that the individual has a 40 per cent or above disability in visual impairment, hearing impairment, locomotor disability, cerebral palsy, leprosy cured, mental retardation, or mental illness. Several informants for this study highlighted the difficulty in obtaining disability certificates. The situation is particularly bad in the north and north-east of the country.

Case study: Karuna Vihar

Karuna Vihar is an organisation working with disabled children in Dehradun. It recently established a help desk once a week at Dehradun Hospital to provide information and advice about obtaining disability certificates. At first, the hospital authorities were resistant to the initiative, but the service has proved very popular with all concerned. Now Karuna Vihar and the hospital are considering establishing a permanent help desk to offer information on a range of other issues in addition to disability certificates.

The Office of the Chief Commissioner for Persons with Disability (OCCPD), headed by the chief commissioner for disability, carries out coordination and monitoring at the national level. A statutory body with quasi-judicial powers, the office and the chief commissioner are required to take steps to uphold the Act, and to act as a forum for redress and grievance in the event of denial of rights.

The Central Coordination Committee (CCC) comprises 40 members from government (including two ministers and three members of parliament), as well as five disabled people representing NGOs and/or DPOs, was also constituted. The role of the CCC is to act as the national policy-making and advisory body. However, no national policy on disability has been formulated since the inception of the CCC, and there have been complaints that until recently the CCC has failed to meet on a six-monthly basis as was stipulated.

The Central Executive Committee (CEC) is the executive arm of the CCC, and comprises 23 members, including five disabled representatives of NGOs and DPOs. Again, there are complaints that the CEC does not meet on a three-monthly basis as stipulated.

State commissioners for disability, state coordination committees (SCC) and state executive committees (SEC) have now been established in all states and union territories (except Jharkand), but some only recently. Nine state disability commissioners have independent charge. The rest assume their disability responsibilities in addition to others.

Complaints abound within the disability sector about the Persons with Disabilities Act itself, and its implementation. Key criticisms include:

- The failure to include certain disabilities under the Act, such as autism, haemophilia, and thalassaemia, and the 40 per cent disability assessment rating
- The lack of any timeframe for implementing provisions under the Act
- Irregular meetings of the CCC and CEC, and failure to publicly disclose minutes of their meetings
- Extremely slow establishment of state commissioners and SCCs and SECs
- The frequent change around of state commissioners and the shared responsibilities of most state commissioners meaning that disability issues cannot be effectively addressed and championed
- The lack of real ‘teeth’ to enforce the provisions of the Act at national and state level
- The fact that no disabled person has ever been appointed as chief commissioner
- The perceived poor performance of the chief commissioners, and the office in general.

It is not the purpose of this report to specifically evaluate the Act and its implementation, but the extremely slow and yet still incomplete realisation of national and state mechanisms (commissioners, SCCs and SECs) suggests a lack of political will by the various governments of India to implement the provisions of the Act. This is not untypical of similar legislation and policy promoting the rights of women and scheduled castes and tribes.

It is within this overall climate that the following achievements of the Office of the Chief Commissioner are noted:

- 7,660 grievances registered, of which 7,483 have been addressed and 177 are under process
- The appointment of state commissioners and SCCs and SECs in all states and union territories but one
- A range of publications, including booklets on inclusive education, better care of children with locomotor disabilities, barrier-free environments, and the provisions of the Act
- National and regional workshops on access for all, employment, education, and redress of grievances
- In most states, awareness-raising initiatives on the implementation of the Act
- Directions issued on the implementation of the Act to various ministries (Human Resource and Development, Urban Development and Poverty Alleviation, Road Transport, Finance, Civil Aviation and Labour), as well as to heads of nationalised banks, universities, chief secretaries of states, and others
- Workshops for school principals and teachers
- Access audits in Delhi, including in 90 per cent of Delhi public schools
- A review of job advertisements for government posts.

At state level, implementation of the Act varies enormously, as shown in the table below.

Implementation of Disability Act in DFID target states *(cont. next page)*

Initiative	Andhra Pradesh	Madhya Pradesh	Orissa	West Bengal
State commissioner for disability	Yes, independent charge SCC and SEC constituted	Yes, independent charge SCC and SEC constituted	Yes, SCC and SEC constituted	Yes, independent charge SCC and SEC constituted
Disability pension	Yes, Rs 75 per month for all disabled 18–65 year olds	No	Yes, Rs 100 per month to those over five years of age, blind, mentally retarded, cerebral palsy, locomotor. Excluded those with family income over Rs 11,000 per year or receiving other government benefits.	Yes, Rs 100 per month to locomotor, mentally challenged, deaf and dumb and blind people who are permanently incapacitated and declared such by a medical board.
Disability unemployment allowance	Yes, Rs 75 per month to unemployed disabled people (18–65 years old) who are on the live registers of the District Employment Exchange. Excluded if household income exceeds Rs 12,000	No	No	No
Medical boards to issue disability certificates in districts	All 23 districts Over 1.5 million certificates issued	No reporting	All 30 districts	All 18 districts Over 650,000 certificates issued
Other	3% employment reservation in government jobs achieved 2000/01 2% reservation in housing built by AP Housing Board Free transport in city and suburban buses in AP State Road	6% reservation of posts (B/C/D) issued by Department of General Administration Employment Exchange in three districts Artificial limbs and assistive devices free	Grants for assistive devices 3% reservation in government jobs Ramps in state buildings Access committee formed instructions on access issued	3% reservation for government jobs Initiatives taken on access 10% increase in number of beneficiaries for assistive devices 10 disability identification

	Transport Corporation	Visually impaired receive free bus transport, and reserved seats on buses for disabled people		camps per district 100% distribution of Disability ID cards by 2004 Sensitisation on disability

Source: Office of Chief Commissioner for Persons with Disabilities (2004)

The state of Karnataka has been nationally recognised as leading the way on implementing the Persons with Disabilities Act. The state commissioner and assistant commissioner have been exceptionally active, and are now working as consultants advising other states on implementation. The success of the state has been built on strong partnerships with civil society organisations and concerted efforts to sensitise all branches of government including the judiciary (see box below).

Case study: Office of Commissioner for Disabilities, Karnataka *(cont. next page)*
Karnataka was one of the first states to appoint a disability commissioner, and has been consistently proactive. It regularly organises a national conference for state disability commissioners to share best practice, and at the January 2005 conference was recognised as a model office. The Karnataka disability commissioner and assistant commissioner have been acting as advisory consultants to other states for nearly six years.

The main achievements of the office include:
- Sensitisation of the judiciary
- All state judges having received training on the Persons with Disabilities Act
- Orientation for lawyers
- All new lawyers receiving sensitisation on the Act and on dealing with disabled people on their enrolment day
- Sensitisation of the bureaucracy
- Sensitisation and training for all levels of state officials, from clerks to chief secretaries, on the Act and dealing with disabled people
- Legal support for disabled people
- Teaming up with students at the National Law School who have established the Alternative Law Forum, which offers free legal advice, conciliation and mediation services for disabled people every Wednesday at the Office
- Linking up with Voices, an NGO that will provide free legal services, including lawyers, for all disabled people so that they can access the courts. All cases will be considered, not only those related to disability issues
- A nodal committee to oversee the implementation of the 1987 Mental Health Act, in compliance with an order from the Supreme Court of India (Karnataka is the only state to have done this)
- A disability voluntary service
- Encouraging volunteers from around the world to come and assist the office, to compensate for the limited number of staff
- Teaming up with disabled people, architects and the media to conduct access audits of public buildings and to encourage enforcement

- Commissioning social audits, usually carried out by a team headed by a volunteer, to assess whether organisations receiving government money are performing well. Mental health facilities, public health and rehabilitation services have been audited
- Undertaking an outreach programme, recognising that most disabled people cannot come to the office to lodge complaints. The commissioners travel to districts to listen and rule on grievances. Local heads in areas such as transport, health, education, and the police are also present to answer complaints. The system of *loc adalat* (public hearings) is widely used throughout the country to deal with grievances relating to women, scheduled tribes and castes, but so far only Karnataka, Pondicherry and Goa have used these public hearings in the area of disability
- Universalisation of sign language, and encouraging its use. All commissioners have learned sign language.

The National Trust Act 1999

This Act aims to protect people with the seven impairments excluded under the 1995 Persons with Disability Act. It recognises that there are disabled people who will require care throughout their lives, and enables parents, relatives and organisations to request the appointment of a guardian for severely disabled people. The Act also provides for the bequest of property by parents of disabled children for future protection of their children after death.

National Human Rights Commission (NHRC)

The National Human Rights Commission acts as a mechanism for redress of human rights violations – particularly institutional violations and discrimination. Unlike the OCCPD, it has powers to litigate, and includes two sitting judges from the Indian Supreme Court. It also has powers to award compensation. It has a large army of staff and 72,000 complaints were handled in 2004.

In 2002, the NHRC appointed a special rapporteur for disability who is visually impaired. Special rapporteurs already existed for women, *dalits*[5], child labourers and bonded labourers. The disability special rapporteur also acts as the Indian nominee of the International Coordinating Committee of the national Human Rights Institution, under the UN High Commission for Human Rights for the draft UN Convention on the Rights of Persons with Disabilities. The NHRC immediately takes cases around the interpretation of the Persons with Disabilities Act, and has recommended amendments to the law. It has investigative powers with a human rights cell in every state. It also conducts research and training on human rights, including disability, for government, law enforcement agencies, lawyers, teachers and civil society organisations.

The special rapporteur sees engagement with, and the capacity building of, disabled people's organisations (DPOs) as a critical part of the NHRC's work, consulting with them and encouraging and supporting them to develop their own positions on key issues. The NHRC has put forward recommendations with a disability perspective to the government on two important prospective pieces of legislation: the Rural Employment Bill and the Right to Information Bill.

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[5] Beneath the four main castes in India society is a fifth group known as the Dalits, which means oppressed, downtrodden and exploited. (Definition from www.dalits.org)

The special rapporteur felt that the NHRC was currently compensating for the ineffectual performance of others. She felt that the CCC was not working as a government coordination mechanism, and the disability movement at the national level was also weak, somewhat divided and immature: “What the disability movement should be doing is largely done by us” (interview 2005).

Ministry of Social Justice and Empowerment (MSJE)

This is the key line ministry with responsibility for disability, though there are several other ministries and government departments that are directly engaged with addressing the problem of disability in India, and many have earmarked funds to develop activities concerning disabled people. There is considerable scope for improvement in developing synergies and a coordinated approach. Disability activists see disability issues as somewhat ghettoised within the MSJE. For example, they argue that all education initiatives for disabled children and adults should be under the Ministry of Human Resources. Currently, there is a lack of government oversight on the operations and activities of special schools.

The MSJE is responsible for monitoring the implementation of the Persons with Disability Act and the National Programme for Rehabilitation of Persons with Disabilities (NPRPD). It is also responsible for administering grants to NGOs working on disability issues. NGO applications for funding are submitted at state level, and the state then recommends organisations to the central ministry, where a committee decides on grants.

NGOs consistently complain that the system is very bureaucratic and difficult to access, and that when grants are given, the amount is often considerably less that that originally requested and that payments are slow and irregular. Anecdotal evidence suggests that the extremely slow disbursement of funds has resulted in NGOs having to lay off staff and close programmes. The MSJE budget for disability is consistently under-spent (Times of India 2005).

In 2003, a committee was established to review the guidelines and procedures for the administration and monitoring of MSJE grants. However, new guidelines were issued by the MSJE before the committee reported, and, according to disability NGOs, the committee’s recommendations have never been made public.

Services

Specialist rehabilitation services for disabled people are essential to minimise the impact of individual impairments and enable people to access their rights and entitlements. These services are typically delivered by a combination of state and civil society (local and international NGOs and DPOs) interventions. Such a combination is desirable. The state, depending on its resources and capacity, can provide a basic package and ensure greater coverage, but civil society providers offer higher quality and more responsive services and, in particular, are able to reach out to those with particularly challenging impairments. State and civil society providers alike need to develop synergistic partnerships to ensure effective and appropriate and sustainable services.

The National Programme for the Rehabilitation of Persons with Disability (NPRD) has established a national structure for rehabilitation. There are six national institutions focusing on specific impairments. These function as national centres of excellence and training. They are:

- National Institute for the Mentally Handicapped, Secunderabad
- National Institute for the Visually Handicapped, Dehradun
- National Institute for the Orthopaedically Handicapped, Kolkata
- Ali Yavar Jung Institute for the Hearing Handicapped, Mumbai
- National Institute for Rehabilitation Training and Research, Cuttack
- Institute for the Physically Handicapped, Delhi

These institutes play a major role in training rehabilitation professionals in disciplines such as physiotherapy, occupational therapy, speech therapy, orthotics and prosthetics, and special needs education.

In addition, there are five composite rehabilitation centres (CRCs) and four regional rehabilitation centres (RRCs) located around the country to provide rehabilitation services. The government has also been encouraging the expansion of district rehabilitation centres (DRCs).

Prosthetics, orthotics and assistive devices such as wheelchairs and tricycles are produced by a government company, the Artificial Limbs Manufacturing Corporation of India (ALIMCO). The Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP) provides grant-in-aid to voluntary organisations, Red Cross societies, National Institutes and ALIMCO for purchasing, making and distributing aids and appliances, usually through camps, and subsidised appliances for those who have an income below Rs 5000.

MSJE also supports civil society organisations to provide services to disabled people under the Deendayal Disabled Rehabilitation Scheme. During 2003/04, some 654 organisations were assisted (MSJE 2004, cited in NCPEDP 2004a).

Numerous other civil society organisations also provide services without receiving any government funding. The quality of these services is variable, but several organisations are at the cutting edge of service provision, training and understanding about different kinds of disabilities. Community-based rehabilitation (CBR) is also well established in India.

Case study: Mobility India *(cont. next page)*

Mobility India was established to reduce the wide gap between the need and availability of rehabilitation services in India and other low-income countries. It has adopted a six-pronged strategy, focusing on:

- Training a second generation of personnel
- Rehabilitation services
- Community-based rehabilitation
- Partner support
- Research and development
- Producing low-cost, lightweight aids and appliances.

The organisation has won international awards and wide recognition for its low-cost aids and appliances such as the ‘Jaipur limb’ (see photo) and the ‘pre-fabricated ankle foot orthosis' for children with polio. These aids are manufactured at Mobility's centre in Bangalore by disabled women, and are now being exported to several developing countries in Asia and Africa. They are also training prosthetics and orthotics technicians in neighbouring countries and in Africa.

Case study: Action on Autism

This parents' organisation was founded in 1991 to provide support and services to people with autism and those who work with them in South Asia. It advocates and lobbies for greater recognition and understanding of autism. The organisation has developed a model school for autistic children in Delhi. It provides training and support to parents, and offers a range of training courses, including a one-year specialist course of working with autistic children accredited by the Rehabilitation Council of India. Action for Autism is recognised as an influential player in the global network of autism organisations. Through its website and newsletters, it provides information and support to people around the world.

Despite islands of excellence, rehabilitation services in India are far from satisfactory. First, government services are insufficient to meet the demand, and are overwhelmingly urban based. Second, the assistive devices produced by ALIMCO are of questionable quality, and are often inappropriate for the realities of life in rural India. Better products and services are available from civil society providers, but their coverage is limited. Access to funding from ADIP is not spread equitably across the country. In 2003/04, in 12 states and union territories not one organisation received any funding (NCPEDP 2004a). Third, costs remain a considerable barrier. Finally, most disabled people lack access to information about the availability of services and their entitlements to free and subsidised services and aids.

Responsibility for rehabilitation lies with MSJE rather than with the Ministry of Health, which means, inevitably, that the medical rehabilitation needs of disabled people are still seen as a 'special' rather than a mainstream health issue.

Civil society and government engagement in rehabilitation is generally not in the form of productive partnerships. At one extreme, some NGOs do not engage with government services at all, and prefer to see themselves as offering alternatives, sometimes in an almost competitive manner. At the other extreme, some NGOs are deemed to be little more than subcontractors to the government, compensating for insufficient state responsibility.

The state has also established 'special employment exchanges' to assist the placement of disabled people in work, but only a tiny fraction of those on the registers actually find work. The Ministry of Labour reported that approximately 64,700 disabled people were on the register in 2000, and 3,300 received placements (NCPEDP 2004a). The National Handicapped Finance Corporation (NHFDC) was set up in 1997 to provide low interest loans to disabled people, but:

> "out of *lakhs*[6] of disabled people in search of credit facilities, only a few thousand are able to apply for the NHFDC schemes and even fewer actually get the loan."

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[6] A lakh is 100,000

NCPEDP 2004a, p 26

The NHFDC might be more effective if it refocused its resources towards assisting and enabling disabled people to access mainstream sources of micro credit.

Disabled people's organisations (DPOs)

In India, there is no national cross-disability umbrella organisation. Most informants for this study felt that such an organisation was desirable, but many were unsure whether it was feasible. Disability rights coalitions consisting of organisations of, and for, disabled people have been established in Delhi, Kolkata, Chennai and Bangalore, and there are cohesive disability networks in Gujarat, Maharashtra, Andhra Pradesh, Karnataka, Tamil Nadu, Orissa and Kerala (VSO 2004).

The National Centre for the Promotion of the Employment of Disabled People (NCPEDP) is a high profile DPO with headquarters in Delhi and representation in most states. Its executive director, Mr Javed Abidi, is probably India's foremost disability activist. NCPEDP has established the National Disability Network, which aims to have at least one disability organisation or group in each of India's 593 districts by 2006. However, there is some weakness in the selection of partners, with what seems to be a focus on establishing a partner in every district rather than looking for the right partners. The inherent inconsistencies in the composition, ideology and values within the network members may inhibit its cohesion.

NCPEDP is also the core member of the Disability Rights Group, a Delhi-based informal network that is often at the forefront of advocacy campaigns. NCPEDP is probably the closest thing to a national cross-disability organisation, but it is urban dominated and not representative.

The National Federation of the Blind (NFB) was established in 1970 but disputes over strategy led to the formation of the All India Confederation of the Blind in 1980. Both DPOs have chapters in approximately 20 states. The NFB has a stronger focus on advocacy and is more of a social movement than the AICB, which tends to give equal emphasis to service provision.

The Delhi Association of the Deaf (DAD) was established in 1950, and in 1955 the All India Federation of the Deaf (AIFD) was set up to address issues of national concern. Over the years, rivalries have developed and consequently a new organisation, Deaf Way, emerged in 1990. Deaf Way has more than 42 Deaf Friendship Clubs across India. It raises awareness on deaf issues and works with young deaf people to raise awareness of their rights and important issues such as HIV/AIDS.

In addition, parents' organisations have grown in number and influence. The largest is the National Federation of Parents Associations of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities (Parivaar), which seeks to empower parents to act on behalf of their children. It engages in advocacy and produces a regular newsletter. However, there are disagreements, and another parents' organisation, Action for Autism is critical of Parivaar's understanding of autism. Recently, the parent's organisation Mitram bought a large area of land in Ernakulam district in Kerala. Here, families of intellectually challenged children have established their own community, with its own school, training centre, playground and gardens. The focus is on providing group solidarity.

Divided by impairment-based interests and personal rivalries, and tending to be urban dominated, India's disability movement has not matured. There is tension between organisations of people with physical impairments and those with sensory impairments, with the latter in particular feeling that they are neglected. Networks and coalitions tend to develop from the top down rather than the bottom up, and this raises questions about how relevant and representative they actually are.

Building a disability movement from the grassroots is clearly a long-term process, but it can be done, as ADD India has demonstrated (see box below). It is also essential if the poorest and most marginalised disabled people are to be really empowered.

Case study: Action on Disability and Development (ADD) India

ADD has been working since 1989 to promote the empowerment and inclusion of disabled people in all aspects of life and society. Working in Karnataka, Andhra Pradesh and Tamil Nadu, ADD facilitates disabled people to form effective and democratic self-help groups or sanghas (see photo), and encourages these groups to link with each other to form federations.

Sangha members learn about disability rights, and then go out to raise awareness in their communities through activities such as street plays and songs. They establish their own savings and credit programmes, provide mutual support, and offer a forum where people can share their problems. ADD also assists sanghas and federations to share information and access services, and to engage with government and mainstream NGOs to ensure that the needs of disabled people are recognised.

India's disability movement can unite over major issues – mostly notably, in securing the 1995 Disability Act, and more recently, by campaigning for disability to be included in the 2001 census. However, in general, it is striking that recent lobbying activities have often been centred on issues that are largely peripheral to the needs and lives of the majority of India's disabled population, who are poor and live in rural areas.

For example, certain sections of the disability movement have become very animated over the fact that none of the chief commissioners for persons with disabilities has been a disabled person. The issue has become quite divisive, and though important as a question of principle, it has detracted from sufficient attention being given to the actual performance of the chief commissioner and their office.

Disability activists have increasingly been using the courts to access their rights, often with considerable success. The Indian judiciary and the Supreme Court has been particularly responsive to disability issues, and several informants put this down to the fact that disability is seen as a less 'political' issue than others, such as caste. However a review of recent judgments on disability reveals that the cases that have been brought are predominately on issues that are of most relevance to educated, middle-class urban disabled people, such as access to Indian Airlines and reservations for disabled people in the top bands of the Indian civil service.

As in other countries, there are also tensions about the role of DPOs, whether they should focus solely on advocacy or engage in service delivery, and on the tactics and strategies adopted. SK Rungta, a veteran of the disability movement in India and President of the National Federation of the Blind (NFB), is critical of the tactics employed by some activists, noting that:

> "Currently, people mistakenly believe that direct action brings change, but there is access to decision makers now. Tactics need to be carefully chosen for each issue. There are issues where there is a need to work with the government but others where a confrontational approach is needed."
>
> SK Rungta, President, National Federation of the Blind, interview 2005

For example, the NFB has been facilitating blind people to access their entitlements from local authorities in Uttar Pradesh. The NFB adopts a two-pronged approach: reminding local authorities of the Disability Act provisions, and helping them fill their reservations by identifying disabled people.

The Indian disability movement is not achieving all that it might. There is a need for unity and much greater cooperation. A national cross-disability DPO may not be feasible, or even desirable. India's federal structure means that responsibility for areas that most directly affect individuals' lives, health, education, transport and housing are devolved to states and local government; state-level umbrella DPOs may be more appropriate.

The disability movement also needs to engage more directly with government, by:

- Facilitating disabled people to access their entitlements by providing them with information
- Sensitising government officials about disability and the provisions of the Disability Act
- Assisting local officials to fulfil their responsibilities.

There is need for a more nuanced approach to advocacy, and a more thoughtful selection of issues on which to lobby.

DPO engagement: examples of good practice *(cont. next page)*

Accessibility is one area in which disability activists have had some notable successes. The new Delhi Metro, currently under construction, will be fully accessible. Delhi Transport Company has agreed to buy its first wheelchair-accessible buses, and some of India's leading tourist sites, such as the Taj Mahal, Dili Haat and Humayun's Tomb, have been made accessible.

Samarthya, a two-person DPO, is leading the way. The organisation has adopted a non-confrontational approach, providing training and sensitisation workshops for architects and town planners, emphasising how accessibility benefits everyone, and demonstrating that disabled people can contribute.

Swabhiman, a DPO in Orissa, has demonstrated the effectiveness of information sharing and political engagement. The organisation has established more than 70 self-help groups and has set up a state-wide disability network, with regular meetings at district and block and *gram panchayat* levels (village committee, lowest level of government).

Its successes have included:

- Promoting the sharing of information and coordinated action
- Translating the 1995 Disability Act into simple Oriya
- Engaging with local officials and securing a second medical board in one district and a single-window approach to obtaining disability certificate and implementing the three per cent reservation in government medical institutions
- Getting questions asked in the state assembly on issues such as the failure to promote inclusive education in the District Primary Education Programme and the delays in establishing a Disability Commission.

Swabhiman is also politically astute, and has recognised the need for politicians to see disabled people as a credible vote bank. They have run a workshop for members of the ruling Biju Janata Dal Party that was influential in securing accessible polling booths and accessible information about the elections. The result was that 70 per cent of disabled people voted. The organisation also understands the importance of accurate information and data in changing the minds of policy makers. It has recently completed a telling survey on the domestic violence and abuse of disabled women.

The Association of People with Disability (APD), in Karnataka, is one of India's oldest DPOs. It was started in 1956 by a group of disabled friends who met in a garage with a plan to establish a vocational training centre. APD demonstrates that service delivery is not incompatible with advocacy and disability rights promotion. Indeed, some suggest that the roots of the social model may lie with APD, rather than in the United Kingdom.

APD provides high quality vocational training in marketable areas such as horticulture (see photo), industry and information technology. It has a model inclusive school, educating children with a wide range of disabilities alongside non-disabled children. It also provides therapeutic services, physiotherapy, prosthetics and orthotics, as well as training physiotherapists and technicians and manufacturing appliances and aids.

APD is currently the fabricating agency for ALIMCO in Karnataka, and organises with ALIMCO and the Red Cross bi-monthly camps. Community-based rehabilitation programmes are offered in 20 slums in Bangalore and 150 rural villages. APD's services go hand in hand with the empowerment of disabled people and advocacy, and it encourages and supports the establishment of self-help groups. The current director explains: "It is about leadership of people with disabilities and enabling them to understand the system and the structures and their role in them… Development is all about investment in people" (interview 2005)

Vibrant and effective organisations led and managed by disabled people play an essential role in:

- Challenging the negative stereotypes of disabled people as incapable victims
- Being the voice of disabled people
- Raising awareness of disability issues
- Holding government and society to account, so that they recognise and respond to the rights and needs of disabled people.

However, all the informants for this study were critical of the performance of the disability movement. Several people commented that the movement has enormous potential but that this potential is not being fully realised. A minority even questioned whether an Indian disability movement actually existed. One activist summed things up as: “too much infighting and partisan thought.”

5 Education

In India, education is recognised as being absolutely critical to enable disabled children to realise their abilities, and the government acknowledges that the vast majority have no access to education at all. Estimates vary. The Office of the Chief Commission for Persons with Disabilities believes that not more than four per cent of disabled children are receiving an education, while the Ministry of Human Resource Development (MHRD) and National Council of Education Research and Training (NCERT) puts the figure at less than one per cent (Singhal 2004).

Most out-of-school children, whether they be girls, members of scheduled castes or tribes, or other poor children, are likely to be missing school so they can contribute directly or indirectly to the household economy. However, out-of-school disabled children are far less likely to be doing so, and may well be drawing another sibling out of class – especially a girl – to take care of them. The MDG on universal primary education cannot be achieved without including disabled children.

The Government of India broadly advocates a twin-track approach to educating disabled children. It supports the inclusion or integration of the majority of disabled children into mainstream schools alongside special schooling for the more severely disabled. Historically, the focus has been on special schools. Integrated education began to be advocated in the 1960s and 1970s, but gained real momentum with the Project Integrated Education of Disabled Children (PIED) in 1987, with support from UNICEF.

PIED demonstrated that general education could be geared to meet the educational needs of disabled children. The success of PIED in 10 blocks (administrative level between district and village, also know as taluka or taluk) across the nation shaped the Integrated Education for Disabled Children (IEDC) scheme, which was launched in 1992. IEDC offers financial assistance towards teachers' salaries, assessment, provision of aids and appliances, training of special teachers, physical accessibility, instructional materials, community mobilisation, early detection and resource support.

In 1994, inclusive education entered the international spotlight with the Salamanca Statement, which was signed by 92 countries. Inclusive education entered rhetoric in India, and the IEDC scheme has now evolved into Inclusive Education of the Disabled (IED). The National Policy of Special Education strongly recommends inclusive education, and the concept is widely used in government documents, including the literature of the District Primary Education Programme (DPEP) and of its successor, Sarva Shiksha Abhiyan (SSA). However, there is a lack of clarity and confusion around the concepts of 'integrated' and 'inclusive' education and 'special education needs'.

Singhal (2004 p 11) notes:

> "The shift from 'integration' to 'inclusion' has been linguistic, devoid of engagement with more fundamental issues… In addition the government appears to be conceptualising inclusive education as another alternative system available for children with disabilities."

Inclusive education is a process centred on transforming the teaching styles and learning environment to meet the special educational needs of children, rather than focusing on making the child adjust to an existing system. The emphasis of inclusive education on systemic transformation makes it a key strategy for achieving education for all, and improving the quality of education. For UNESCO, which is the key global player in promoting and developing inclusive education, children with special needs include not only disabled children, but all children who are typically marginalised from the education system. This includes girls, children from minority ethnic groups, working and street children, and gifted children.

In India, the term ‘children with special needs’ is in reality a euphemism for disabled children, some of whom may not actually have any special educational needs. Despite the rhetoric promoting inclusive education, the emphasis remains on adapting the child to the system and not vice versa. The first review of SSA (Sarva Shiksha Abhiyan 2005) emphasises the need for Indian schools to have a greater focus on quality and child-centred teaching. It further notes that IED implementation is poor, and that a medical model of disability still predominates, resulting in an emphasis on identifying and assessing disabled children, and responses focusing on providing assistive aids and improving the physical accessibility of schools with the construction of ramps and rails.

Overall, the emphasis seems predominately to be on getting disabled children into school, with very little attention given to ensuring that once inside the classroom they are receiving an education that is responsive and appropriate to their needs. Educational access for disabled children is important, but without an equal emphasis on meeting their particular needs, disabled children are likely to be ignored and will probably drop out. One informant for this study suggested that the significant financial resources allocated to the SSA programme were actually a problem, noting that there is great pressure on education staff to spend, and be seen to be spending, their budgets. The result is that money is thrown at very visible and easy areas. Shiny new ramps and rails are a suitable quick fix.

Alongside the promotion of integrated and inclusive education, there has been a rapid growth in the number of special schools. In the early 1990s, there were approximately 1,035 special schools, but by 2000 the number had more than doubled to reach around 2,500, with most concentrated in urban areas – particularly in Mumbai (Singhal 2004). Special schools are the responsibility of the MSJE rather than the MHRD. The MSJE provides ‘grants in aid’ to various NGOs to run these schools, though most do not receive any government funding.

Many informants saw the special school system as problematic. First, there was a lack of oversight of special schools to ensure that the curriculum, teaching methods and overall care were of a high standard. Second, some felt that special schools have vested interests, which in practice work against the development of inclusive practices. Finally, others felt that the rapid growth in special schools undermined the development of inclusive education.

Disabled children enrolled in mainstream schools in DFID target states

Andhra Pradesh	**Madhya Pradesh**	**Orissa**	**West Bengal**
17,067	110,000	No data	50,677

Source: Office of the Chief Commissioner for Persons with Disabilities (2004), Sarva Shiksha Abhiyan (2005)

Disabled children who do manage to receive a basic education will encounter significant obstacles should they wish to further their studies. Despite the three per cent reservation in all state educational facilities, only 0.1 per cent of university students are disabled. Most universities are unaware of the assistance they can receive from the University Grants Commission (UGC) to improve accessibility. In a recent survey by NCPEDP, only nine per cent of the universities contacted had received a UGC grant. The situation is only slightly better at college level, where 0.52 per cent of the students were disabled (NCPEDP 2004b).

DFID should be congratulated for including the needs of disabled children as a specific indicator in its agreement with the Government of India. The emphasis on improving educational achievement among scheduled caste, schedule tribe and disabled children, and especially girls among them, is an important inversion, prioritising the most marginalised and multiply vulnerable. However, DFID is a small player, and there remain enormous barriers to disabled children getting equal access to education in India.

6. Conclusions and recommendations

India has proved an excellent final case study for this research examining 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. At the state level, there is comprehensive disability legislation defining rights and entitlements and mechanisms for establishing standards and for monitoring and redress. In terms of specialist services for disabled people, there is a national plan for rehabilitation and significant state engagement in its implementation. In addition, there are numerous civil society service providers, many of whom provide extremely high quality services, and some who are at the cutting edge of their fields, whose work impacts on the regional and global level, such as Mobility India and Action for Autism.

India also has numerous disabled people's organisations (DPOs), many of which have a long history and are led by highly educated and motivated disability activists. Finally, resources – both financial and human – are broadly adequate, and are certainly not 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 on equality of access than on the notion that certain groups are under-privileged and require 'special' assistance.

India's disability legislation was composed in this spirit, and currently the attitude is clearly seen in the key sector of education where, despite the rhetoric of inclusion, the emphasis is still very much on securing access to school for disabled children through providing special aids and constructing ramps and rails. The social welfare approach still dominates most of the civil society organisations working on disability issues, and those that champion disability rights are faced with the vested interests of older and well-established players.

Second, India's disability organisations (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. The majority of civil society informants for this research consistently complained about the government's failure to implement the provisions of the Disability Act, the under-utilisation of government disability budgets, and the failure to fill reservations, while admitting that they do not seek government funding, and broadly ignore state processes and systems. There is no question that corruption is a significant problem, and the Indian bureaucracy is infamously inflexible and complicated, but the criticisms of the state are hard to maintain when so many disability organisations appear to dismiss out of hand the possibility of engagement.

Despite the limited time period, this research discovered several examples of effective cooperation between disability organisations and the state. Partnerships between the state and civil society service providers are critical if rural disabled people are to have access to the appropriate and affordable aids, appliances and rehabilitation that they need.

Third, India's disability rights movement has 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. Moreover, the sheer size, complexity and diversity of India may well preclude the creation of a strong, national, cross-disability organisation. However, there are very positive developments at the state level, with strong disability networks evolving. The National Centre for the Promotion of Employment for Disabled People (NCPEDP) is emerging as a focal point for national-level advocacy.

Nevertheless, many of the issues that disability activists raise are unfortunately 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, planned government legislation on a minimum income for rural workers, and the right to information, are given insufficient attention.

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

SWOC situation analysis of disability in India *(cont. next page)*

Strengths	**Opportunities**
• Comprehensive disability legislation • Mechanisms for monitoring implementation and redress (chief commissioners, National Human Rights Commission) • Adequate financial resources • National rehabilitation plan, 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 DPOs 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)	• 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
• Patchy implementation of disability legislation (reservations in employment, education and poverty alleviation programmes not filled, disability budgets under-utilised) • Difficulties in obtaining disability certificates, accessing government funding • Confused understanding of inclusive education • Disabled people lacking information about rights and services • Disability organisations coopted 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 not representative, top down, urban focused • Lack of strong, coordinated disability movement	• Corruption • Monolithic Indian bureaucracy • Size and complexity of India

Returning to the conceptualisation of disability mainstreaming as a three-legged stool (see p 30), 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 subcontractors or are 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 crossovers demonstrate the relevance of disability to poverty reduction and national development. Furthermore, they are essential if disability is to break out of its' special' enclave. Two such examples are highlighted below.

Case studies: real disability mainstreaming *(cont. next page)*

UNNATI is a well established NGO in Gujarat, providing capacity building to organisations involved in community development. The organisation became aware of disability following the Gujarat earthquake. Staff began to increase their knowledge of disability issues and gained an understanding of the links between disability and poverty. The organisation was alarmed by the lack of engagement between disability organisations and wider civil society. There were rehabilitation and specialist services for disabled people, but no one seemed to be addressing the overall context and environment.

To address the problem, UNNATI worked with 13 mainstream NGO partners to carry out a survey of the situation of disabled people in five districts in Gujarat, using participatory rural appraisal techniques. The survey raised awareness and became a collective learning process for all involved. Since the completion of the survey, four of the mainstream NGO partners have introduced disability into their work at no extra cost.

UNNATI has also been linking with disability organisations to provide training on barrier-free environments, and has been conducting access audits of public buildings in Gujarat. It now works with multiple stakeholders, encouraging ownership of disability issues by all duty bearers, and facilitating linkages between mainstream organisations, disability service providers and DPOs.

Samadhan is a small disability organisation working to support intellectually challenged children in two slum areas of Delhi. The organisation quickly began to realise that the mothers of these children were so poor that they had little time or interest in helping their children develop. Samadhan established a mother's self-help group, where mothers provide mutual support, receive education, information and vocational training, and take part in income-generation activities. Samadhan empowers the women, who are then enabled to support the development of their intellectually challenged children. "I have more freedom. I can take decisions since bringing my child to the centre", said one mother. Children learning at Samadhan's centre are pictured.

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, the country's performance on the Millennium Development Goals is critical. In a sense, donor aid may not be very important to India, but India is very important to donors.

India is DFID's largest country programme. Although some support is given to the Government of India for national programmes, the majority of DFID's assistance is targeted at four of India's poorest states: Andhra Pradesh, Madhya Pradesh, Orissa and West Bengal. 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 make an impact. Disability is firmly located within this context.

The DFID country office and programme in India have been exceptionally proactive on disability issues. The initiatives that the office has taken have been driven by a small number of staff with a particular interest in disability, and individuals downplay their significance. Despite progress being at an early stage, DFID India has taken some steps that offer a potential model for other DFID country offices to follow. The key features of DFID India's response to disability are:

- **Inclusion of disability indicators in logframe agreements with the government** Disability indicators are included in the agreement with the government for the Sarva Shiksa Abhiyan (SSA) programme, which DFID is supporting along with the World Bank, and the European Commission. The agreement emphasises the need for improved educational achievement for scheduled tribe and caste children and disabled children, and particularly girls within these groups. The emphasis is innovatory because it focuses on the most marginalised and those who are multiply disadvantaged. Disabled people are also included in the logframe for the multi-donor Reproductive and Child Health Programme. This programme requires states to identify groups with the worst health outcomes, and to channel resources accordingly. There will be triangulation of monitoring, including community monitoring, which is accorded equal status.

- **INGO partnership** 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 (VSO) is the nodal agency for disability. The international NGO partnership is at an early stage, but so far VSO has assisted DFID, by organising a roundtable meeting where the Secretary of State met key disability stakeholders. VSO also arranged the schedule for this research so that the demands on DFID India staff were minimal.

- **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. DFID has adopted a 'hands-off' approach. The management of the programme is handled by a management agency of Development Alternatives with PricewaterhouseCoopers. Flexibility and responsiveness are built into the programme. CSOs submit an initial concept note, and then if that is accepted the managing agency works with them to develop a full proposal. The proposal can still be adjusted within the first three months, and again after a year. Monitoring is participatory and non-threatening. The programme originally had a sectoral thematic design, but this has been dropped in favour of a holistic approach.

  The programme is encouraging real capacity-building approaches. One informant described PACS as "a marvellously thought out programme". Disability was not originally included in the PACS, but Development Alternatives has recognised that poverty cannot be addressed without talking about disability. Four disability organisations are receiving PACS funding at present, and proposals are being developed with others, including DPOs.

- **Implementing DFID's corporate diversity agenda** DFID India has also been proactively seeking to implement the corporate diversity strategy, and disability is seen as a priority area. DFID India invited NCPEDP to observe its recruitment processes and make recommendations on how to ensure they are open and inclusive. Efforts have been made to ensure the accessibility of the office. There is much to do, and there has been little success so far in getting disabled people to apply for posts. However, the process is at an early stage, and staff are aware of shortcomings and are actively seeking solutions.

- **Tsunami response** DFID India is planning to develop advisory support on issues of social exclusion and an independent social/equity audit capacity for post-tsunami rehabilitation programmes. The purpose is to ensure that recovery programmes pro-actively address issues of social exclusion and negative discrimination affecting the poorest. Disability is included, and a DPO will be involved in the social/equity auditing process.

DFID's programme in India is exceptional in terms of its size and its innovatory 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 towards disability issues does offer a model that other country offices may find interesting and relevant.

Recommendations

DFID India has already lost some of the individuals who have so successfully championed disability issues, and will shortly be losing more. Their departure brings a risk that disability could once again drop off the radar screen. There is a long way to go before disability issues are truly mainstreamed and institutionalised within DFID India. Nevertheless, the key recommendation is for the country office to continue as it has begun. Below are some suggestions for building on what has already been achieved.

Support research into the links between disability, poverty and development. The World Bank is currently undertaking a major survey of disability in India, focusing on the socio-economic impact of disability. It is to be applauded for taking the initiative, and the results will play an important part in addressing the lack of hard data on disability.

DFID may wish to consider ways in which it can support the World Bank in this survey. This could be done through a light approach – for example, by facilitating contacts with disability organisations with which DFID is involved through the INGO partnership and the PACS programme.

After the completion of the survey, DFID could explore options for working with the World Bank to ensure that the findings are widely disseminated and that the key issues identified are raised and addressed in future development planning.

Finally, DFID might like to consider supporting disability research directly, perhaps following up on gaps and issues identified in the World Bank's survey, or in emerging and neglected areas. In the course of this research, the need for research into the violence and abuse of disabled women has been raised several times.

Another glaring gap is on HIV and AIDS and disability. There is a growing body of evidence showing that disabled people, and especially disabled women, are particularly vulnerable to contracting HIV. Disabled people also lack information on how to protect themselves and lack access to services (Groce 2004, Yousafzi and Edwards 2004). However, in India, only two organisations working with disabled people had considered the issue at the time of writing. Deaf Way referred to research that identified sex workers living with HIV and AIDS who mainly dealt with deaf clients in Mumbai and Calcutta. This report estimated that 200,000 deaf people in India are living with HIV and AIDS (MacArthur Foundation 2001).

Include a disability clause in all agreements for funding with civil society.
The DFID Civil Society Challenge Fund (CSCF) requires all applicants to demonstrate how their proposed activity will be inclusive of disabled people. DFID India could include a similar requirement in all programmes providing support to civil society.

Include disability-specific indicators in agreements with the government.
Continue the practice started with the SSA and Reproductive and Child Health programme.

Encourage DPOs and disability organisations that have a rights-based approach to seek funding from civil society support programmes.
DPOs and disability organisations are often unaware of funding opportunities from mainstream donors such as DFID, and the procedures for accessing such funding. DFID India might like to consider ways to encourage DPOs to apply for funding. For example, through the INGO partnership, VSO could organise brief workshops in Delhi and in DFID target states to inform DPOs and disability organisations about funding opportunities.

Include representatives from DPOs and disability organisations in external consultations, and in community monitoring of DFID-supported programmes.
The disability perspective cannot be assumed. Disabled people need to be consulted.

Ask questions about the implementation of the disability legislation.
The 1995 Disability Act provides three per cent reservations for disabled people in poverty alleviation programmes, government posts, and in state educational facilities, as well as other rights and entitlements. DFID may wish to enquire about what progress is being made towards the full implementation of the Act, especially in DFID target states.

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Annex 1: List of interviewees

DFID India

Joanna Reid	Senior Health Adviser
Roger Cunningham	Senior Education Adviser
Sandhya Kanneganti	Social Development Adviser, West Bengal Programme
Geeta Unnikrishnan	Social Development Adviser, Orissa Programme
Jiji Bhattacharji	Deputy Head, Human Resources

British Council

Kalpana Das	Manager, Governance and Social Justice
Kamal Singh	Head, Governance and Social Justice
Neeti Malhotra	Deputy Head, Governance and Social Justice

World Bank

Philip O'Keefe	Lead Social Protection Specialist

UNICEF

Chetana Kohi	Project Officer, Education

International NGOs

Kevan Moll	Country Director, Voluntary Service Overseas
Alana Officer	Country Director, Handicap International
R Ramachandran	Country Director, Action on Disability and Development
Akhil Paul	Director, Sense International
Dal Naidu	Country Director, Basic Needs, India
Mr Gururaghavendra	Basic Needs, India
Dr GN Narayana Reddy	Chairman, Richmond Fellowship
Singhal Mr Vasudeva Murthy	Coordinator, Richmond Fellowship
Kevin John Noronha	Programme Officer, Action Aid, Karnataka
Christa Abraham	Regional Manager, Action Aid, Karnataka

Local NGOs

Pramila Balasundaram	Founder, Samadhan
Dr Krishna Vasta	Director of Projects, Samadhan
Geeta Sharma	Director, UNNATI
Deepa Sonpal	Programme Coordinator, UNNATI
Colin Gonsalves	Executive Director, Human Rights Law Network
Kiran Sharma	PACS Manager, Development Alternatives
Dr Ali Baquer	Executive Director, Concerned Action Now
Victor Cordiero	Programme Manager, Sabala
Harsh Mander	Centre for Equity Studies
Michael Sanjivi	Director, Mobility India

Disabled people's organisations and parents' organisations

Rama Chari	Senior Programme Officer, National Centre for the Promotion of Employment of Disabled People (NCPEDP)
Jo Chopra	Director, Karuna Vihar
Merry Barua	Director, Action for Autism
Arun Rao	Director, Deaf Way
Madhu Singhal	Director, Mitra Jyoti

Sanjeev Sachdeva	Founder, Samarthya
Anjlee Agarwal	Executive Director, Samarthya
SK Rungta	President, National Federation of the Blind
Dr JP Gadikari	President, Parivaar
VS Basavaraju	Director, Association of Persons with Disabilities

Governmental and quasi-governmental bodies

Dr Laxman Malodia	Project Director, Gujarat Aids Control Society
Dr Uma Tuli	Chief Commissioner for Persons with Disabilities
Dr Andradha Mohit	Special Rapporteur for Disability, National Human Rights Commission
Pradeep Kumar	Assistant Commissioner for Persons with Disabilities, Karnataka

Others

CS Mohapatra	Former Director, Ministry of Social Justice and Empowerment
Dr Kamala Gidwani	Medical Superintendent, GTB Hospital, Delhi and Deputy Medical Commissioner, ESIC

Annex 2: Terms of reference

Objective
The objective of this assignment is to provide DFID-India with access to information and recommendations that can guide policy and implementation practice to reduce vulnerability and achieve higher levels of social inclusion for disabled people in its work with the Government of India and other partners, such as the World Bank and civil society groups.

The second objective is that this information will be used as part of a three-country study to help DFID develop policies and processes to mainstream disability.

Scope of work
India was selected, following consultation, as one of the three countries for the DFID Action Research because the DFID India office has been particularly proactive in seeking to include the needs of disabled people, and is in the early stages of developing potentially interesting models of cooperation to support mainstreaming of disability issues.

In order to be responsive to the particular needs of India, the following country-specific research objectives have been framed:

- Review and examine the current situation of disabled people and the status of disability issues in India, including:
  - the scale and nature of disability in India, drawing on existing quantitative and qualitative data, the work on developing the World Bank Disability Issues Report, the DFID Disability Roundtable of December 2 2004, and the Disability KaR Roundtable of February 2005
  - legislative and policy commitments of the Government of India on disability issues the main providers of support for disabled people and the organisational arrangements that make this possible
  - the effectiveness of current channels for advocacy on behalf of disabled populations.

- Map current disability-focussed activities in India (including those carried out by government, multi-lateral and bi-lateral development agencies, civil society organisations) and identify examples of best practice.

- Review and examine the current and planned DFID India's disability initiatives within its wider work on social exclusion and discrimination and, in particular, the INGO partnership programme.

- Identify potential partners to assist DFID India with future programme development focused on reducing vulnerability.

- Review and examine the opportunities and constraints for DFID India to further develop partnerships with others (World Bank and civil society) to support policy and programme change and implementation by the Government of India to reduce the vulnerability and social exclusion of disabled people.

- Review and examine the opportunities and constraints for mainstreaming disability issues within existing programmes of DFID India with minimal costs and input.

Methodology

- The Disability Policy Officer of the DFID Disability KaR Programme, Philippa Thomas, will be the principal researcher. The research will be carried out in the UK and in India. The Disability Policy Officer will be assisted in the in-country research by a local assistant researcher, who will be able to assist the Disability Policy Officer in the following areas:
    - identifying interviewees, especially from local civil society organisations
    - facilitating meetings
    - interpreting interviews as required
    - providing local contextualisation and understanding.

The Disability Policy Officer will be responsible for:

- communicating with DFID India and ensuring that all relevant DFID HQ staff are kept fully informed
- liaising closely with VSO India over the schedule of the research
- identifying and reviewing key documents
- identifying a local research assistant, working with them to develop their workplan, and managing them
- conducting in-country research, involving reviewing documents, conducting semi-structured interviews with key DFID personnel, international and Indian stakeholders and programme and project field visits
- preparing an India country report
- providing technical support to country offices in identifying means to take any recommendations forward.

Specific activities

- holding a seminar for DFID India and invited guests to present preliminary findings
- carrying out semi-structured interviews with DFID India staff and partners
- conducting interviews with other donors, faith-based organisations, NGOs, the Government of India, and disabled people’s organisations.

Role of DFID country offices

The Disability KaR programme and the Disability Policy Officer do not wish to inconvenience or significantly add to the workload of the DFID India in conducting this research activity. However, it is hoped that DFID India could offer the following support to the Disability Policy Officer in conducting the research:

- providing information on the work of the country office in addition to information already available on Insight and PRISM, as appropriate
- ensuring the participation of key country office staff, through semi-structured interviews.

All costs associated with the research will be covered by the Disability KaR Programme.

The Disability Policy Officer will be responsible for all logistical arrangements (including travel to and within country and accommodation) for in-country visits.

Outputs

- Country report containing:
  - a summary of the current situation of disabled people in the country and initiatives addressing disability
  - examples of best practice and a list of potential partners and key country contacts
  - recommendations for DFID India to take forward its work on reducing the vulnerability and social exclusion of disabled people to share with the partners and the Government of India
- Identification of a network of support partners for DFID India
- Case study material to inform DFID's planned policy on social exclusion and strategy for inclusive development.

Timing

Desk studies of secondary sources will be made in advance of the visit to India.
The visit to India will be for two and half weeks beginning from March 7 2005.
The seminar will be given one day before departure.
The report will be presented in draft form to the Senior Social Development Adviser, DFID India within one month of the completed visit.

Activity	**Completed by:**
Final terms of reference agreed	end of January 2005
Local researcher identified	mid-February 2005
UK-based desk research (up to 10 person days) and in-country research, including preliminary report (up to 21 person days)	end of March 2005
Country report completed	end of April 2005

Reporting

While in India, the Disability Policy Officer will report to the Senior Social Development Adviser.

Background

The Disability Policy Project is one of several components of the DFID Disability Knowledge and Research (KaR) Programme.

The goal of the Disability Policy Project is to assist DFID to develop policies and processes to mainstream disability and to ensure that the Disability KaR's knowledge and research outputs are responsive to DFID's needs and effectively communicated to DFID. The Disability Policy Officer is based within Central Research Department, but links primarily with DFID's Diversity Adviser, DFID's Gender and Human Rights Adviser and the newly established Exclusion, Rights and Justice (ERJ) team within Policy Division in DFID HQ.

The first major output of the Disability Policy Project was the completion of a mapping study of DFID's current work on disability, *DFID and Disability: A mapping of the Department for International Development and disability issues* (DFID 2005).

This mapping report aimed to provide a snapshot of what DFID was currently doing to address disability issues and it identified the following key issues:

- DFID has not mainstreamed disability, but there is a solid bedrock of disability-specific activities being carried out, largely via NGOs and civil society organisations (CSOs).
- DFID's work on disability is largely hidden, and often DFID staff and country offices are unaware of disability-focused activities being carried out by NGOs and CSOs.
- While broadly recognising the links between poverty and disability, DFID staff do not necessarily see disability as an essential part of their work on poverty reduction and the achievement of the Millennium Development Goals (MDGs).
- DFID staff need more information on disability – in particular, practical tools and examples of best practice – to enable them to implement the twin-track approach outlined in DFID's 2000 issues paper *Disability, Poverty and Development* (DFID 2000).

Mainstreaming Disability in Development (MDD) Action Research
It is proposed to build on and extend the initial DFID mapping by conducting three pieces of action research on disability mainstreaming in three countries where DFID works.

The generic research objectives for the study are:

- to explore how three DFID country offices see the issue of disability in relation to their work on poverty reduction, social exclusion and the MDGs
- to explore how the inclusion of disability issues can contribute to the reduction of poverty and social exclusion and the achievement of the MDGs
- to map what three DFID country offices are currently doing to address disability issues and identify examples of best practice[7]
- to identify opportunities and potential partners for each DFID country office to take forward work on disability, particularly in relation to key sectors such as health and education
- to inform the development of a planned DFID policy on exclusion and the Exclusion, Rights and Justice (ERJ) team's workstream on inclusive development.

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[7] The identification of best practice could extend beyond the work of the DFID country office to include government, development agencies (bi-lateral and multi-lateral) and NGOs/CSOs.